University of Alberta

Social Relationships from the Perspectives of Persons with Developmental Disabilities, their Family Members, Educators, and Employers

by

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Abstract

Social relationships are an essential component of community living for any individual, especially those with developmental disabilities. Many researchers have touched on the topic of social inclusion, but most often with a focus on the school-age population or the perspectives of parents or teachers. Few studies have examined the experiences of the adult population or the viewpoint of persons with disabilities themselves. The purpose of this dissertation was to explore the social relationships that persons with developmental disabilities of all ages have in school, work, and leisure settings, and examine the importance of these relationships according to these individuals. Archived data from the Inclusion Across the Lifespan project helped to gain insight into the social lives of individuals with developmental disabilities. In an attempt to further describe the social experiences of the persons with disabilities, six cases from the Inclusion Across the Lifespan project thought to best represent the different developmental stages were chosen and supplementary interviews using arts-based techniques (i.e., participant-produced drawings) were conducted with the six key participants. Each participant's "story" was presented as a case study, and cross-case comparisons were made following the presentation of the cases. Within each case, several types of relationships—including friendships, family relationships, relationships with support personnel, and community relationships—were described in detail. Furthermore, the benefits of social inclusion to persons with disabilities as well as other community members were reported. However, despite these benefits, each participant continued to face social challenges. Several future implications were spawned because of these results: (a) the need for social-skills training and structured social activities, (b) the recognition of the crucial role of informal social

supports such as those in some rural communities, (c) the need for researchers to rework the definitions of *inclusion* and *friendship* to include the elements presented in these case studies, and (d) the need for further methodological considerations in qualitative research of this nature to include the perspectives of persons with disabilities.

Dedication

To my two precious babies,

may you always know the joy of friendship and love of family.

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Finally, to my Lord God, for His unfailing love and guidance through both difficult and celebratory times, I give my deepest gratitude.

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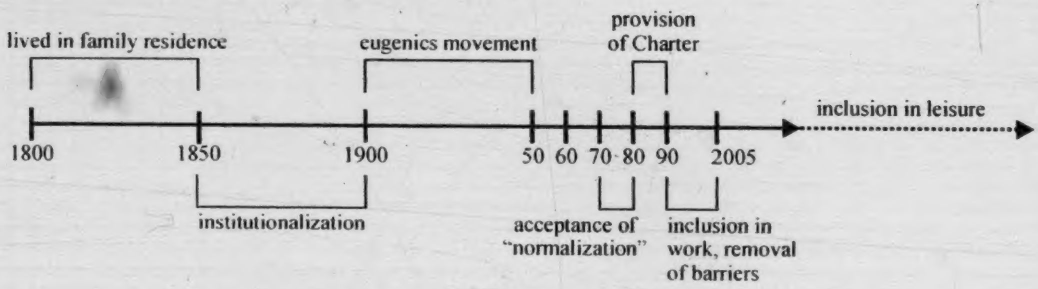
CHAPTER 1: INTRODUCTION

Historical Overview

Treatment of Persons with Disabilities in the Community

Prior to the 20th century, a common practice for Canadian authorities was to place individuals with developmental disabilities in institutions. This institutionalization occurred from the 1850s through the turn of the century (see Figure 1). Before that, most individuals with disabilities were raised in their family homes with little support or involvement in the community. Attempts were made between 1900 and 1950 to enlighten professionals; however, the eugenics stronghold prevented movement into regular activities, and segregation continued (Andrews & Lupart, 2000). In the 1970s the National Institute on Mental Retardation promoted Wolfensberger's (1956; 1970) concept of normalization that focussed on inclusion of people with disabilities in as normal an environment as possible. Support for this concept was formalized in the 1980s when the Canadian Charter of Rights and Freedoms brought in new legislation, and Canada became one of the first countries to guarantee rights to persons with disabilities. Today the trend continues, with inclusion being practiced more than ever before. The Federal Office of Disability Issues has initiated programs to remove barriers and improve the social and economic inclusion of persons with disabilities (Hutchinson, 2002). Progress is evident in that 56.3% of individuals with disabilities were participating in the workforce in 1991 compared to 48.5% in 1986 (Fawcett, 1996). This rate is still lower than the 57.6% of people without disabilities who are employed, but the gap is narrowing.

Figure 1. Timeline of community inclusion.

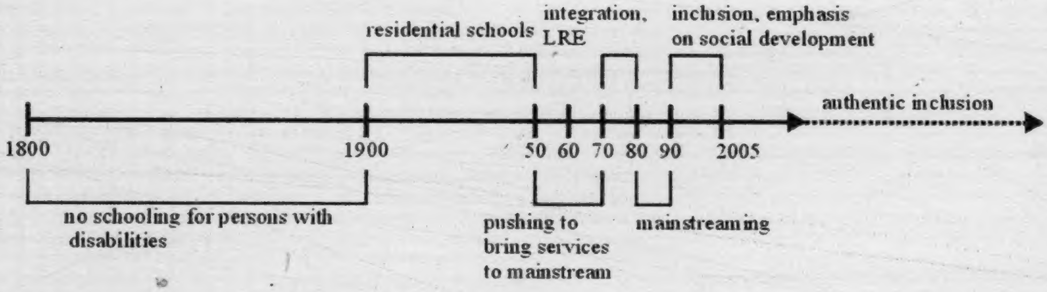

lived in family residence
eugenics movement
provision of Charter
inclusion in leisure
1800
1850
1900
50
60
70
80
90
2005
institutionalization
acceptance of "normalization"
inclusion in work, removal of barriers

Treatment of Persons with Disabilities in the Schools

For the first half of the 20th century, persons with developmental disabilities were generally not served in public education systems, and residential schools were their primary placement, thus separating children with disabilities from their nondisabled peers. A push to improve educational provisions for students with disabilities and bring the services into the mainstream took place in the 1950s and 1960s. The five-box special-education approach (i.e., referral-testing-labelling-placement-programming) was widely implemented and used to categorize students with exceptional needs and make informed decisions on the best placement for these students; this model remains predominant in many Canadian schools today (Andrews & Lupart, 2000). Although this shift brought many students with disabilities into the same classroom as their peers, the stigma associated with their labels and the lack of support in the classroom continued to segregate them socially.

In the 1970s there was a conceptual shift from an emphasis on traditional segregated special education to one of integration (Andrews & Lupart, 2000). This broad-based focus influenced school practice by advancing the belief that education of all students should take place in the least restrictive environment, which was generally assumed to be the regular classroom (Lister, 1999). During the next decade (i.e., the 1980s), the concept of integration moved towards the concept of mainstreaming (Andrews & Lupart, 2000; Figure 2). Mainstreaming focussed on the reintegration of students with disabilities in the regular classroom through intensive efforts (i.e., individualized program plans) to ready the students for the demands of the mainstream (Coutinho & Repp, 1998). However, two barriers hindered this process: (a) the preoccupation with categories and (b) the increasing divide between the regular and special education systems (Andrews & Lupart, 2000). Once again, students with disabilities were placed in the same settings as their peers, but labels remained an obstacle.

Figure 2. Timeline of school inclusion


residential schools
integration, LRE
inclusion, emphasis on social development
authentic inclusion
1800
1900
50
60
70
80
90
2005
no schooling for persons with disabilities
pushing to bring services to mainstream
mainstreaming

Starting in the 1990s and continuing today, inclusion is often considered the ideal for persons with disabilities (Figure 2). The United Nations Education, Scientific, and Cultural Organization has identified a right to education for all individuals, including those with disabilities. It is important to note that the societal view shifted from changing the student to fit the environment to adjusting the environment to accommodate the student (Mittler, 2001). Concomitant with the movement toward inclusion in education was the emphasis on the social development of persons with disabilities (Figure 2). Over the past two decades, considerable research has focussed on friendships and the social acceptance of people with disabilities. Indeed, social inclusion is currently viewed as equally important as educational inclusion.

Rationale for the Study

Social relationships, especially friendships, are critical to the emotional, social, and physical well-being of individuals with disabilities. People with disabilities who have friends are more likely to have a positive self-concept, a sense of belonging, better communication skills, healthier emotional functioning, more positive coping strategies, improved problem-solving ability, a better grasp of life skills, enhanced social cognition, and reduced behavioural outbursts (Geisthardt, Botherson, & Cook, 2002; Heiman, 2000; Schleien, Heyne, Rynders, & McAvoy, 1990; Schleien, Ray, & Green, 1997; Smith, 1981; Stainback & Stainback, 1987). Unfortunately, compared to their nondisabled peers, people with disabilities tend to have fewer friends and less stable relationships (Pavri, 2001; Siperstein, Leffert, & Wenz-Gross, 1997; Zetlin & Murtaugh, 1988). This lack of companionship often results in the increased likelihood of emotional/behavioural disorders (Schleien et al., 1997), greater rates of victimization, and lowered self-concept, (Cullinan, Sabornie, & Crossland, 1992).

A person's self-concept and its influence on the quality of life of the individual with a disability must not be overlooked. Children, especially those with challenges, must be able to see themselves in a positive light as they develop and gain the ability to view their own flaws and limitations in a constructive fashion while trying new approaches to gaining friends (Andrews & Lupart, 2000). A low self-concept often results in self-rejection and self-contempt (Rosenberg, 1965) and can damage the social life of an individual. If someone suffers from low self-concept, sadness, depression, and loneliness may result (Overton & Rausch, 2002). In addition, low self-concept can lead to poor physical and mental health (Coleman, 1992; Orvaschel, Beeferman, & Kabacoff, 1997) and, sometimes, even decreased longevity (Heyne, 1997). Zolfaghari (1999) has shown that high self-concept promotes the maintenance and enhancement of health. In contrast, Kehle and Barclay (1979) described the poor outcomes for people with disabilities who experience low self-concept. The individuals in their study had a death rate seven times higher than that of the norm population and were more likely to be unemployed. If they did find employment, there was a high likelihood that it would be in low-income, low-skill positions.

Another important consideration is that self-concept affects behaviour (Yauman, 1980). "What a person believes about himself affects what he does, what he sees and hears, and his capacity to cope with the environment" (DeFrancesco & Taylor, 1985, p. 99). Without adequate self-concept, individuals are unable to engage in self-evaluation at either a general or a specific behavioural level (Stipek, Recchia, & McClintic, 1992). One possible outcome of this inability to self-evaluate is increased criminal behaviour (Kehle & Barclay, 1979). Individuals with adequate or high self-concept, however, are motivated to perform and act in a socially appropriate manner (Hill & Ritchie, 1977).

Given the importance of social relationships in a person's life, an exploration of social inclusion and, particularly, social relationships seems timely to further understand the social lives of individuals with developmental disabilities. It is essential that persons with developmental disabilities be given the opportunity to form friendships so that they too can harvest the benefits and avoid the consequences of rejection and isolation.

Summary of Previous Research

In the past, researchers have measured the self-concept of individuals with developmental disabilities in both inclusive and segregated settings (Duvdevany, 2002; Hyde, 1982; Kahn, 1983; Long, 1997; Maieano, Ninot, Bruant, & Bilard, 2002; Silson & Harter, 1985; Stainback, Stainback, East, &7 Sapon-Shevin, 1994; Zemke, Knuth, & Chase, 1984). Unfortunately, their results have varied, and there has been little consensus on the environmental conditions that foster positive self-concept. In addition, these results have been almost exclusively quantitative in nature and have given little description of the social experiences of the individuals in these environments. A qualitative approach to this problem will shed more light on this topic by providing rich descriptions of the contexts and the experiences within these environments. This type of inquiry will allow individuals with disabilities to discuss their social relationships and how these relationships make them feel about themselves without putting a quantitative value on the emotions. Jersild (1960) stated, “It is necessary to know more about an [individual] than can be gained from self-rating inventories if we are to be reasonably sure of what might be his conception of self” (p. 54).

Other studies have examined peer acceptance of children with disabilities in inclusive environments (Cheung, 1990; Diamond, Hestenes, Carpenter, & Innes, 1998; Forlin & Cole, 1994; Freeman & Alkin, 2000; Gillmore & Faring, 1989; Jamieson, 1987; Reed, 1984). However, many of these studies have focussed solely on preschool and school-age groups, resulting in a paucity of research aimed at the adult population. Social inclusion does not begin and end at school; it applies to individuals of all ages and, ideally, participation in the community continues throughout the lifespan. To understand social inclusion as it is experienced across the life course, we must examine all age groups.

Furthermore, researchers have focussed on parents' perspectives (Guralnick, 1995; Kasari, Freeman, Bauminger, & Alkin, 1999; Palmer, Borthwick-Duffy, Widaman, & Best, 2000; Stahmer, Carter, Baker, & Miwa, 2003) and teachers' attitudes toward inclusion (Denti, 1999; Engelbrecht, Oswald, Swart, & Eloff, 2003; Hastings & Oakford, 2003; Janzen, Wilgosh, & McDonald, 1995). Many researchers have described the importance of representing the "voice" of children and adults with disabilities in the study of social inclusion (Allan, 1999; Brown, 1999; Goode 1999; Mittler, 2000; Timmons 1999); but still, few studies have focussed in depth on the attitudes and perceptions of individuals with disabilities.

Purpose of the Study

This multiple-case study of social inclusion will contribute to the knowledge of the social lives of persons with developmental disabilities. The purpose of this research was to explore the types of social relationships that persons with developmental disabilities have in school, work, and leisure settings and to further understand the importance of their social relationships to them. An arts-based technique (i.e., participant-produced drawings) served as a catalyst during the interviews to allow the participants to discuss their experiences in a more tangible, concrete manner. I chose the key participants from six different age groups in the Inclusion Across the Lifespan project (preschool, 3-6; child, 7-12; adolescent, 13-17; young adult, 18-30; adult, 31-50; older adult, 51+; see Appendix A) to represent the major stages of life. Archived data from the Inclusion Across the Lifespan project (i.e., participant, parent/guardian, and teacher/ employer interviews) were an additional information source in this study to gain a fuller understanding of the social experiences of these individuals. I identified common themes within each case, as well as across cases (Stake, 2006) and then used them to describe the social experiences of individuals with developmental disabilities and the importance of these relationships to each participant.

Stakeholders

This research has many stakeholders, the first of whom are individuals with developmental disabilities. It is of utmost importance to give individuals with developmental disabilities a voice in the research community. This research project provided such a forum for the participants to state their needs and desires to improve their lives in the community. In addition, the families and caregivers also hold a stake in the project in identifying the social needs and resources that are essential in the social lives of their loved ones. Outside of the family circle are the stakeholders within the community. Agencies such as the Alberta Association for Community Living will be very interested in the results of this research project, which has the potential to provide the informed direction that many of these agencies need to support their agendas of community inclusion.

Research Questions

To anchor this research to the outlined purposes, I posed several guiding questions:

1. What types of social relationships exist for individuals with disabilities in school, work, and leisure settings?
2. What is the self-perceived importance of these social relationships?
3. What role do these social relationships play in the key participants' lives?
4. How do the parents/guardians and teachers/employers view these social relationships?

CHAPTER 2: LITERATURE REVIEW

Introduction

Social relationships are essential components to community living. Without these relationships, one is at risk for loneliness, depression, illness, and maladaptive life skills. It is of utmost importance that the social relationships of persons with developmental disabilities be understood to allow researchers and other professionals to foster better social relationships between persons with disabilities and the people in their lives. In this literature review I explore past research that has focussed on the social relationships for persons with disabilities and the factors that had a potential impact on these relationships. First, I define *social inclusion* and the abstract terms of *friendship* and *self-concept*. Next, I explore the benefits of social inclusion and the potential barriers that persons with developmental disabilities may encounter in their quest for social inclusion. Finally, I examine the key research findings on the topic of social relationships for persons with developmental disabilities through the lens of Bronfenbrenner's (1967) socio-ecological theory and Festinger's (1954) social comparison theory. Three key areas of research emerge within this discussion: (a) the impact of certain contexts on social relationships, (b) peer acceptance of persons with disabilities, and (c) descriptive analyses of the types of social relationships that individuals with disabilities have.

Definitions and Constructs

Social Inclusion

Social inclusion allows an individual the ability "to develop and maintain reciprocal social relationships based upon trust and mutual caring that transcend specific settings or contexts" (Abery, 1997, p. 4). This definition differs from the definition of inclusion that many researchers use in examining the education of persons with disabilities. Most often the focus of inclusion is on setting—the placement of children in "regular" environments. Social inclusion, however, can occur in any number of contexts. It gives people a feeling that others care for, value, and want to spend time with them and assures them that support will be provided when they need it (Abery, 1997). On numerous occasions, attempts have been made to operationalize this term, but because of the highly personalized nature of social inclusion, this task has proven to be virtually impossible. Social inclusion is not static; the degree to which one needs or wants social interactions varies from person to person (Abery, 1997).

Friendship

Friendship is a mutually preferred and enjoyed affective tie between two individuals that requires three attributes for it to exist: (a) the friends freely choose each other, (b) the friendship is mutual and reciprocal, and (c) the friendship is expected to endure (Heyne, 1997). Friendships are stable and offer intimacy, companionship, and emotional support (Freeman & Kasari, 1998). Moreover, the interactions between friends are personal, and the individuals involved are not merely filling predefined roles; they are interacting as unique individuals (Clegg & Standen, 1991). As with social inclusion, researchers have attempted to operationalize the concept of friendship. For example, Romer and Berkson (1980) defined a friend as someone with whom target participants spend more than 3% of their time. However, this type of definition ignores the intimacy that is necessary in a friendship. Many individuals with whom a person spends more than 3% of his/her time could be filling other roles such as paid support. Instead, O'Brien and O'Brien (1993) suggested that friendship is best explored through talking to the active participants in a friendship rather than relying on a detached observer. This approach also helps researchers to understand whether it is friendship that is being referred to or another type of social relationship.

Other Social Relationships

Many persons with developmental disabilities have a number of relationships in their lives, but most of them are with family members, acquaintances, and people who are employed to interact with them (Heyne, 1997). Sometimes the individual with a developmental disability will identify these persons as friends (Clegg & Standen, 1991), but there are usually qualitative differences in the nature of these relationships. Family members and service providers often feel an obligation to have relationships with the person who has a disability and, therefore the mutuality of the friendship definition may be missing. Furthermore, acquaintances may at times appear to be friendly, but they share a lower level of social engagement with and responsiveness to one another (Siperstein et al., 1997). This is not to say, however, that these social relationships cannot develop into friendships over time. Friendships can emerge from various social relationships with family members, staff members, co-workers, and neighbours (O'Brien & O'Brien, 1991). Over time, intimacy and reciprocity can develop, and what was once an acquaintance, staff member, or relative could now be identified as a friend.

Self-Concept

Self-concept is derived from people's environment and reflects the way that they perceive themselves in a social context. It is an identity term that reflects the performance expectancy. These perceptions are formed through experience with the environment (e.g., friendships) and are reinforced by the evaluations of others (Fischer, 1994). In recent years authors have highlighted the importance of viewing self-concept as a multidimensional construct. To use a unidimensional model is to ignore individual constructs identified in specific domains of life (van Gurp, 2001). Individuals do not usually have equally high or low self-concept across all dimensions (e.g., academic self-concept, physical self-concept); thus, it is important that we make distinctions between the different dimensions to foster those aspects that need the greatest enhancement.

The Importance of and Challenges to Social Inclusion

Benefits of Friendships and Social Inclusion

Friendships and social inclusion allow individuals of all abilities to share affect, support, companionship, and compassion (Heyne, 1997) and provide a sense of belonging and personal fulfillment to an individual (Reidy, 1993). Inclusion in community activities also promotes the learning of social skills, which lays the foundation for later friendships. Cole and Meyer (1991) reported direct evidence to support this stance: children with developmental disabilities, who were socially included in regular classroom events, scored higher on the Assessment of Social Competence Scale than did children who were placed in a segregated environment.

Aside from social skills, individuals with developmental disabilities can learn appropriate behaviour and self-help skills when they are socially included (Schleien et al., 1990; Schleien et al., 1997). Individuals with developmental disabilities who are included in natural social environments develop a sense of how to cooperate with others, what makes others happy and unhappy, and what they must do to gain the cooperation of others (Ensign, 1993). A person with special needs may also learn motor, perceptual, and academic skills (Ensign, 1993), which are all proficiencies that educators spend many hours trying to teach, but it appears that children may learn them best through inclusion with their age peers.

Furthermore, friends provide support to individuals with developmental disabilities when they need it. For example:

> Friends look out for each other, friends help each other, and friends don't let you get put away in an institution no matter how pretty the picture is painted by someone who says it's for your own good. Friends know better. Friends can speak up for you if you are too shy or nervous to do it, and friends can give you the confidence you need to do it yourself. (Shea, 1987-1990, p. 2)

Friendship provides a "safety net" (Turnbull & Turnbull, 1991) to many individuals with disabilities and acts as an important network throughout a person's life.

Not only do individuals with developmental disabilities benefit from social inclusion, but so does everyone else around them. The families of children with developmental disabilities often feel less isolated when their child is socially included. If parents are able to develop friendships with families of nondisabled children, they can learn about typical development and gain support from other members of the community (Wolery & Wilbers, 1994). Nondisabled peers who have an opportunity to become friends with persons with developmental disabilities learn more realistic and accurate views of disability (Wolery & Wilbers) and have a model of people who may have overcome challenges. For example, in one case study Myers (1991) described an incident in which a child with a developmental disability acted as a role model for his nondisabled classmate: "For Ryan, knowing Karl allows him to think through what's important about learning, about being the best and not being the best, about trying hard, and about being a friend" (p. 26). Additionally, the parents of children with typical needs have an opportunity to teach their children about differences and how to accept these differences

(Wolery & Wilbers, 1994). In the adult population, the benefits of social inclusion have been shown in the workplace. Employers have reported that employees with disabilities, who are socially included, demonstrate camaraderie and commitment to their work that can inspire and influence those who work with them (Labelestra, 1991).

Barriers to Social Inclusion

Though current researchers have reported many benefits of social inclusion, numerous barriers to this inclusion still exist and make it difficult for individuals to benefit from participation in their community. The field of social inclusion has two types of barriers: external and internal. The external barriers to social inclusion include external forces such as physical obstructions or negative attitudes, the latter of which places additional pressure on the child with a disability and makes the disability a further challenge for the individual (Schleien et al., 1997). Internal barriers are limitations that the child with a developmental disability may have (e.g., lack of social competencies, lack of leisure skills, and lack of functional skill development as a result of the child's disability). I believe that overcoming external barriers may better accommodate internal barriers.

Physical barriers. Probably the most obvious external barriers to the social inclusion of individuals with developmental disabilities are the physical barriers in many settings, such as inaccessible entrances to buildings, crowded rooms, and even lack of transportation. Many individuals with disabilities face the challenge of finding transportation just to be able to attend community activities (Komissar, Tufts, & Hart, 1991).

Attitudinal barriers. One external barrier that is common in many environments is the resistance of teachers and other professionals. Even though research and legislation support social inclusion, educators and other community members are reluctant to move into this new model (Moore, 1997). Many adults fear inclusion because they have little knowledge about disabilities and do not clearly understand the needs of children with developmental disabilities (Weiss & Karper, 1980). Children develop their attitudes based on the attitudes of the adults around them, and for nondisabled children to interact successfully with children with developmental disabilities, adults need to model positive attitudes toward individual differences. In addition, we need to allow persons with disabilities to have a "voice" and self-advocate. Unfortunately, this is often not allowed, and, thinking that they know what is best for that individual, parents or other adults usually speak for the person with a disability. Day and Harry (1999) discussed one case in which a participant "remained a silent participant whenever her disability became the topic" (p. 227). Instead of seeking input from the persons with disabilities, assumptions about their needs and wants are made without any clarification.

To add to this obstacle, there are often myths and misunderstandings surrounding the topic of social inclusion, such as the folklore that friendship does not matter to persons with developmental disabilities because they lack the ability to understand or that persons with developmental disabilities have too little in common with their nondisabled peers to develop meaningful friendships (O'Brien & O'Brien, 1993). Such myths allow society to downplay the social relationships of persons with disabilities and place little value on their friendships:

> [They say,] "Isn't it nice that you have your *little* friends to play with?" When a friend got sick and you ask to go the hospital and see him, they acted like you

> were fooling. And sometimes a friend got moved away without even having a chance for us to say good-bye (perspective of a person with a developmental disability; O'Brien & O'Brien, p. 19).

In addition, these misconceptions can lead others to believe that the person with a disability is too much of a burden (Komissar, Tufts, & Hart, 1991), thus leading to a reluctance to build friendships with these individuals.

Inadequate training. Lack of training and adequate consultation make social inclusion more difficult because the people involved with the individual with a developmental disability may not know of strategies to use in various environments (Wolery & Wilbers, 1994). Many university programs do not provide training to work with individuals with disabilities unless a student focuses on a career in special education. Also, many schools, workplaces, and leisure settings do not employ professionals from the field of special education or other related rehabilitation fields unless the program is specialized for persons with disabilities.

Lack of funding. The social inclusion of persons with developmental disabilities sometimes involves modified programs, specialized equipment, and staff training, which create a need for more resources. Provincial and federal funding has not increased accordingly to provide these modifications, and often families cannot afford the expense of specialized equipment and programs. Additionally, families are afraid to ask for too much and hesitate to reach out for support because funding is continually cut or unavailable (Schoeller, 1997).

Confusion about definitions. An abundance of terms is used to describe persons with developmental disabilities, which makes it difficult to specify the needs of these individuals and address them properly (Wunderlich, Rie, & Amado, 2002). Terms are frequently too generic, and individuals who are very different from each other are often lumped into the same group. For example, the broad term *mentally handicapped* is often used to refer to any individual with a cognitive deficit. However, cognitive disabilities are diverse and can affect the individual in a number of different ways. The label of *mentally handicapped* includes many types of disabilities (e.g., brain injury, genetic syndromes, global delay).

On the other hand, other definitions are disability specific and often inadequately exclusive. They do not focus on the individual needs of the person that may fall outside of the diagnostic label. Again, individual needs get lost in the labels. For example, children with Fetal Alcohol Spectrum Disorder are expected to display specific characteristics such as the typical facial features, behaviour problems, and learning disabilities. These individuals may, however, have additional needs related to other aspects of their being, but such needs are not addressed because family members, teachers, employers, and support staff focus only on the characteristics of Fetal Alcohol Spectrum Disorder. Often the social needs of individuals with developmental disabilities are overlooked unless a social deficit is listed under the definition of their disability.

Spread phenomenon. A barrier that is related to the definition dilemma is the *spread phenomenon* (Makar Murphy & Murphy, 1997). Because of the generic definitions of many disabilities, some people assume that if there is one disability at hand, other disabilities must surely be present. A common example of the spread phenomenon is people's assumption that children with cerebral palsy have a cognitive disability simply because of their mobility impairments. This assumption could easily impede social inclusion because of the misunderstandings that occur.

Theories and Models

A number of theories on the abstract concept of social inclusion can assist researchers in better understanding this complex notion. In this section I present two theories relevant to the social inclusion of individuals with developmental disabilities. The first is Bronfenbrenner's (1967) socio-ecological theory, which demonstrates the importance of context in a person's development (see Table 1). The role of context is of utmost importance in the social development of all individuals, including those with developmental disabilities. Second, I consider the social comparison theory (Festinger, 1954), which demonstrates that some contexts may not meet all of the social needs of individuals with disabilities.

Socio-Ecological Theory

As depicted in Table 1, Urie Bronfenbrenner's (1967) socio-ecological theory identifies the complex layers of an environment that have an effect on an individual's development (Slee & Shute, 2003). The processes that affect development are the joint function of biological characteristics and the processes within the environment (Bronfenbrenner, 1995; Srouffe, Cooper, & DeHart, 1992). An individual's world is composed of four layers, as shown in Figure 3: the microsystem, the mesosystem, the exosystem, and the macrosystem. Progression through these layers can help or hinder the development of an individual, including social development. The following discussion describes each layer of the socio-ecological model and explains how it specifically applies to social development. Following this description and an examination of the contrasting social comparison theory (Festinger, 1954), I will examine the current social inclusion literature and the applications of these models within those research findings.

Table 1

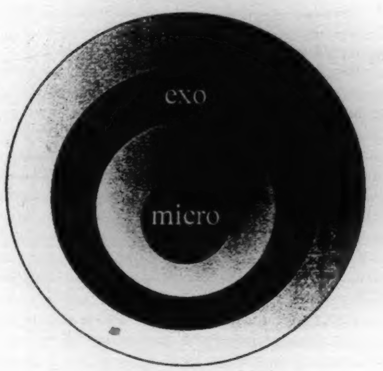
Summary of Bronfenbrenner's Socio-Ecological Model

Layers of the environment	Bronfenbrenner's application (1967, 1993, 1995)
Microsystem	• Immediate face-to-face settings • People, symbolic features, and interactions within the settings • Features can have favourable or unfavourable effects on development
Mesosystem	• The linkages and processes between Microsystems • Experiences in one microsystem affect experiences in another
Exosystem	• Settings that indirectly influence the development of the individual
Macrosystem	• Overarching culture • Subcultures exist and may differ in norms from the culture (Srouffe et al, 1992)

The first layer of the socio-ecological model is the microsystem, the immediate face-to-face setting that an individual encounters (e.g., school, work, or leisure settings). It includes the people present, the symbolic features, and the interactions or activities within the setting (Bronfenbrenner, 1995). Microsystems have specific and particular physical, social, and symbolic features that invite, permit, or restrain development and behaviour. Social interactions can either be encouraged or inhibited depending on the features of the immediate social setting.

The second layer of the model, the mesosystem, comprises the linkages and processes that take place between microsystems. Srouffe et al. (1992) claimed that these interactions between systems in the community (i.e., schools, workplaces, and leisure settings) have a definite influence on developmental areas, including social factors such as self-concept and social competence. What occurs in one setting can have an effect on the interactions in another. For example, children who are raised in abusive family situations may be more withdrawn at school than they would have been had they been reared in supportive family atmospheres.

Figure 3. Bronfenbrenner's (1967) Socio-Ecological Model.



Third, the exosystem is the larger social system in which the individual is not directly involved but, is influenced by. Although the focal persons are not active participants in these settings, the exosystem activities can change the characteristics and activities of the microsystems. For example, school administrators can create policies that determine the characteristics of some classrooms (e.g., class composition, number of students, curriculum, and schedules).

Finally, the fourth layer, the macrosystem, includes the overarching culture that encompasses the microsystems, mesosystems, and exosystems (Figure 3). It includes the belief systems, lifestyles, and patterns of social interchange (Bronfenbrenner, 1993). The culture may include subcultures with different norms and values from those of the overarching culture, which, consequently, may lead to some confusion. One example of this challenge is presented when individuals from one culture live in a country that practices different traditions and beliefs. This could, at times, make social interactions with those from different cultural backgrounds difficult because differing beliefs and rituals may interfere with shared activities.

Social Comparison Theory

Related to Bronfenbrenner's discussion of context, Festinger (1954) claimed that the characteristics of some contexts could be detrimental to an individual's social functioning; namely, his/her self-concept. Social comparisons are those that individuals make between themselves and others in an attempt to generate self-evaluative information (Schwalbe, Gecas, & Baxter, 1986). They base these evaluations on their immediate comparison group (Coleman, 1983; Morvitz & Motta, 1992; Schurr, Towne, & Joiner, 1972). At times such comparisons can help to maintain self-concept, but they can also have the opposite effect and lower self-concept. Theorists who support segregation assume that individuals with developmental disabilities placed in environments with their mainstream peers compare themselves to individuals of higher abilities, which could result in a deflated self-concept (Coleman, 1983; Elbaum, 2002; van Gurp, 2001). They have argued that deficiencies among individuals with developmental disabilities become more apparent when they are placed in a general classroom and compare themselves to their nondisabled peers (Bear, Clever, & Proctor, 1991).

Key Research Pertaining to The Role of Context in the Social Lives of Persons With Developmental Disabilities

Inclusive vs. Segregated Contexts

Since the promotion of Wolfensberger's concept of normalization (1970), many researchers have focussed their efforts on determining the impact of setting on individuals with developmental disabilities and their social standings. Within this literature is an ongoing discussion of the importance of context, thus lending itself to interpretation through the lens of Bronfenbrenner's (1967) socio-ecological theory. The literature on the inclusion or segregation of individuals with developmental disabilities can be related to one of Bronfenbrenner's four levels of environments (i.e., microsystem, mesosystem, exosystem, or macrosystem; see Table 2 for a summary).

In analyzing the immediate environments in which individuals participate, Bronfenbrenner (1974) explained that some microsystems contain specific regions that are unfavourable to the development of individuals with specific characteristics. Inclusion advocates assert that segregated classrooms, sheltered workshops, and special programs constitute such microsystems and can result in unfavourable development of persons with developmental disabilities. Additionally, Bronfenbrenner (1993) reported that "the same cognitive processes, in both children and adults, varied appreciably both in complexity and efficiency as a function of the context in which they are embedded" (p. 38). Interactions with peers with disabilities (i.e., in the segregated environment) will not have the same outcome that interaction with peers both with and without disabilities will have (i.e., in the inclusive environments). Because many persons without disabilities have appropriate and effective social skills, individuals with disabilities can learn from their peers and gain skills that assist them in leading a productive social life (Heiman, 2000). Furthermore, being provided with opportunities to interact in various community settings (i.e., microsystems) can result in increased opportunities to meet potential friends.

Table 2

The Application of Inclusive Ideology to Bronfenbrenner's Socio-Ecological Model

Socio-ecological model	Bronfenbrenner's (1967, 1993, 1995) application	Examples within inclusion ideology
Microsystem	• Immediate face-to-face settings • People, symbolic features, and interactions within the settings • Features can have favourable or unfavourable effects on development	• Interactions with peers with disabilities have a different outcome than interactions with peers both with and without disabilities do • Segregated settings have unfavourable effects on development
Mesosystem	• The linkages and processes between microsystems • Experiences in one microsystem affect experiences in another	• Home and school interact to assist with inclusion • Positive experiences in the inclusive classroom will result in positive experiences in other community activities (Simpson & Meaney, 1979)
Exosystem	• Settings that indirectly influence the development of the individual	• Advocacy groups collaborate with school boards to assist social inclusion
Macrosystem	• Overarching culture • Subcultures exist and may differ in norms from the culture (Srouffe et al., 1992)	• Inclusion acts as a supporting subculture that teaches realistic self-appraisal (Bacher, 1964) • Segregation acts as a contrasting subculture that teaches contradictory norms

Social inclusion at a young age is important for a child's first intrapersonal experiences. Children who take part in play with their peers at preschool have an opportunity to develop their self-concept and self-awareness (Smith, 1981). If, however, children are separated from their preschool peers, they may become agitated and depressed (Field, 1981). In Guralnick, Connor, and Hammond's (1995) study, virtually all mothers stated that, in the inclusive classroom, their children with disabilities made gains in learning to share, resolving conflicts, and playing cooperatively. Despite wanting their children to have more friends, the mothers stated that their children learned more from their nondisabled peers than they would have from children in a segregated setting. They valued such a setting because of the presence of peers and the opportunity for their children to interact with their peers (Guralnick et al., 1995). Furthermore, when mothers of children who were place in segregated settings were interviewed, they expressed a desire for a choice of placement for their children in which they would have an opportunity to interact with nondisabled peers. They saw some value in the segregated program but wanted their children placed in inclusive settings (Guralnick et al., 1995). Elementary teachers appear to agree; they rate the regular class as more effective in fostering social relationships (Hamre-Nietupski, Hendrickson, Nietupski, & Sasso, 1993). In contrast, if social inclusion does not happen during the school years and individuals are not allowed to have experiences in the same microsystems as their peers, it becomes very difficult to make friends as adults: "The older you are and the longer you wait, the more difficult [social inclusion] becomes" (Turnbull & Ruef, 1997, p. 218). In one case (Day & Harry, 1999), two adolescent girls were not able to describe how or when they had become friends; it was their proximity to each other over a long period of time that had allowed the friendship to form.

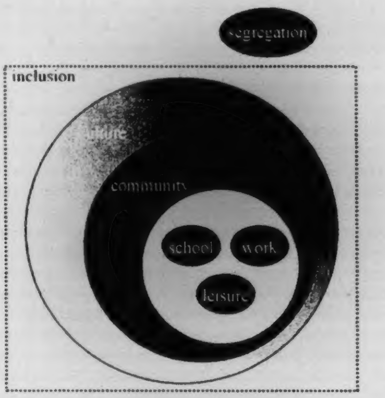
Another important consideration is the influence of the interaction between microsystems on an individual (i.e., mesosystems). With regard to social inclusion, one could argue that regular classroom placement could benefit children with special needs when other support systems such as work, home, or other community settings are available to assist in the process. Experiences in one setting can influence the individual's experiences in another context (Figure 3). For example, if a child with a disability has had positive inclusive experiences in the past, he/she is more likely to succeed in other inclusive environments (e.g., sports or leisure activities). As evidence, Simpson and Meaney (1979) confirmed the need for socially inclusive opportunities in microsystems such as their five-week ski program. They found that physical activity and success in the activity are a potential source of reinforcement for future success and enhanced self-concept.

On a broader scale, school boards, government agencies, and other authorities act as an exosystem in the lives of many persons with disabilities. Frequently, these factions form policies and procedures that are followed in schools and communities. Many disability advocacy groups (e.g., Alberta Association of Community Living) are aware of this influence and, through close collaboration and cooperation with school boards and government agencies, have made it their mandate to ensure that individuals with disabilities are socially included. With support from the leaders at the administration level (i.e., the exosytem), individuals with disabilities can lead more productive and rewarding social lives.

Finally, social inclusion allows individuals to learn ways of realistically appraising themselves so that they can function in their overarching culture (i.e., the macrosystem; Bacher, 1964). According to Abery (1991), cultural membership largely influences an individual's experience of social inclusion, either negatively or positively. Hatch (1993) described this concept within the "work culture." He stated that work settings contain a culture of their own and have shared meanings, expectations, and values that set the social atmosphere of the work environment. The employees who "fit in" socially are more likely to be accepted by co-workers and viewed as successful by their employers.

Segregation, however, can act as a subculture that teaches individuals contradictory norms and values that result in confusion and frustration as they struggle to "fit in" (Figure 4). In 1967 Bronfenbrenner found that African Americans who were segregated from their peers tended to think of themselves as unwanted or ugly. Similarly, students with disabilities who are placed in the subculture of a segregated classroom have to contend with the stigma associated with special-class placement (Elliot & McKenney, 1998; Johnston, 1994). Identifying children as exceptional and isolating them from a larger population will diminish self-concept because of the stigma that these labels perpetuate (Coleman, 1983). Stigmatization can lead to deprivation of the opportunity to adapt to one's culture in which one will live (Bacher, 1964).

Figure 4. Socio-ecological model of inclusion.



Contrary to these arguments, however, other researchers have focussed on the possible negative impacts of socially inclusive contexts. According to Schnorr (1997), students with developmental disabilities in secondary schools have significantly lower self-concept scores than do their nondisabled peers. Duvdevany (2002) concurred and found that the physical self-concept of adolescents with developmental disabilities who participated in segregated recreational activities was higher than that of individuals who were involved in inclusive activities. Similarly, Zemke et al. (1984) found that participation in a segregated camp program showed a significant increase in the individuals' overall self-concept. In these cases, those with disabilities were able to compare themselves to others more like them, which thus lends support to Festinger's (1954) social comparison theory. However, these results must be interpreted with caution because there was no control group and the increase in self-concept could have resulted from the individuals' being part of a camp rather than part of a segregated program.

Ribner (1978) and Coleman (1983) reported similar findings for the elementary school ages in their focus on school settings. Lower self-concept was evident among the children in regular classrooms when academic difficulties were apparent. Additionally, Coleman found that individuals with disabilities in segregated classrooms rated themselves higher on the popularity scale than did the students in the regular classroom. In the preschool population, Guralnick, Neville, Hammond, and Connor (2007) found that children with developmental disabilities initiated interactions more frequently than their nondisabled peers did because their initiations were less successful or the interactions were shorter. The children with disabilities did not seem to have the social knowledge to initiate successful interactions and thus were more apt to view themselves as less competent than their nondisabled peers.

An In-Depth Look at Specific Social Contexts

Church. In recent years some researchers have shown interest in the support that natural or existing networks can provide. Many church settings are examples of such a network because churches often have a built-in subculture of a diverse group of people interested in supporting and helping one another (McNair & Swartz, 1997). According to Sarason (1977), religion is an organizing factor in many communities, that provides an easy network for individuals who have difficulties accessing other avenues of support. Hence, I argue that church acts as a microsystem that permits and invites positive social interactions. In addition, this microsystem can interact with other community organizations that influence social interactions and thus provide a mesosystem that influences the social lives of persons with disabilities. McNair and Swartz (1997) examined the way in which church, as a setting, offers support to individuals with developmental disabilities. The four main sources of support that church staff reported include (a) integration into religious classes, (b) opportunity for the person with a disability to take part in services, (c) emotional support, and (d) assistance with basic needs. Similarly, Trulear (1997) reported that one church program provided opportunities for its members with disabilities to gain confidence and leadership skills so that they were able to take on future leadership roles within the church community. This research, however, relied on the reports of church staff and discussions on how their churches "served" persons with disabilities. There is some question as to whether this type of support can be considered social inclusion or "charity." The perspectives of persons with developmental disabilities needs to be examined to better understand the role that church plays in their lives.

Work/volunteer settings. Other researchers have explored the social inclusion of individuals with developmental disabilities in the workplace. According to Stewart (1985), work settings are the second most important social unit in many people's lives, with family often being the first. As stated previously, Hatch (1993) suggested that work settings contain a culture (i.e., macrosystem) of their own and have shared meanings, expectations, and values that set the social atmosphere of the setting. In many cases this social atmosphere can be one of acceptance and positive social interactions. Test, Hinson, Solow, and Keul (1993) found that 97.1% of employees with developmental disabilities reported having a co-worker as a friend. In addition, 38.1% of the participants reported having opportunities to socialize with their co-workers after work hours. Chadsey and Beyer (2001) found that some work cultures are more conducive to social inclusion than others. Employees with disabilities can fill many "meaningful" positions, either paid or volunteer. Bauer (1997) stated that effective placement is a matter of finding the right "fit" between a person and his/her job. Some of these jobs, according to Monissar, Tufts, and Hart (1997), naturally lend the support needed.

College. Since the emergence of the inclusion initiative, more and more persons with disabilities are attending college, whether to earn a diploma/degree or to advance their skill sets. Few studies, however, have acknowledged this new trend, and there is insufficient literature available to fully examine social inclusion in the postsecondary setting. The literature that is available often examines individual programs and the successes or failures of those particular settings. In one case study, Doyle (1997) found that, despite intentions to provide equal access and equal opportunities to post-secondary students with disabilities, the nondisabled students tended to pity those with disabilities. They felt that they had to "take care of" or "be nice" to the students with developmental disabilities, hence interfering with the formation of friendships. In this case it seems that the symbolic features of that particular microsystem restrained rather than encouraged peer interactions. However, these results must be interpreted with caution because it is only one example and does not necessarily represent all college programs.

Home. The home environment is often overlooked as a socially inclusive setting, but it could be one of the most important settings for children to build social relationships. According to Stoneman (1993), "It is of little value to facilitate interactions in the classroom if children with disabilities spend the rest of their time socially isolated in their homes and neighbourhoods" (p. 242). As Bronfenbrenner (1967) alluded to in his description of mesosystems, there is a need for interactions between the home and the school system for social inclusion to be successful. Successes in the home setting can lead to successes in other community settings such as school or work. Unfortunately, however, research findings suggest that social inclusion in the home environment is not always achieved. Gesithardt, Brotherson, and Cook (2002) found that, according to parent reports, 3 out of 28 children aged 4 to 10 ½ played with other neighbourhood children every day, and 7 out of 28 children played with other neighbourhood children occasionally. In addition to these low numbers, six mothers believed that children without disabilities were fearful of their children because of their differences.

For adults with disabilities, interactions in the home environment can be difficult. Many individuals with developmental disabilities live in residences, either with family or in a group home, that offer little privacy and routines or schedules that interfere with social interactions (O'Brien & O'Brien, 1993). In addition, if support staff are present in the home, they may pass along comments about the individual's disability that could influence others' perceptions, or they may make decisions regarding what is best for the individual with a disability by focussing mostly on physical well-being and placing little emphasis on social relationships (O'Brien & O'Brien, 1993). This treatment often results in a microsystem that is not conducive to social interactions. According to Pottie and Sumarah (2004), however, this is not always the case. In their study of L'Arche communities (i.e., a disability advocacy group aimed at supporting inclusive home environments), individuals with disabilities had many successful social experiences in their home settings. The L'Arche communities emphasize frequency of contact, personal values, and a personal quality of fidelity, all important factors that help individuals with disabilities to maintain bonds with their peers. Rather than stifling community contact, these communities use strategies that encourage friendship: "The culture of the community reflected a number of shared values" (p. 62).

Another aspect that needs to be considered in studying social inclusion in the home setting is the characteristics of the towns in which the participants live. In their study, Geisthardt et al. (2002) found that two families attributed their child's lack of community interaction to the fact that they lived in the country and did not have any immediate neighbours. They felt that the community members were not familiar with their children. In contrast, however, another mother reported that living close to a busy road was an obstacle for her child because there were too many dangers to contend with, and he was, therefore, not allowed as much freedom as he would have been had his family lived in a less busy part of town. Along the same line, Ralph and Usher (1995) discussed the advantages of living in a rural community, which is better defined and has higher rates of interpersonal interaction because there are more opportunities to meet neighbours and other community members. Many rural organizations (i.e., exosystems) value community acceptance and community member involvement; therefore, they strive to create a community environment that values all residents. Because of this influence, rural communities can act as a microsystem, which is more conducive to enhancing the opportunities for social interactions for persons with disabilities. On a broader scale, many rural communities also contain their own subcultures or macrosystems in which individuals with disabilities "fit in."

Peer Acceptance of Individuals with Disabilities

There is often a concern that placing individuals with disabilities in regular classrooms or socially inclusive work or recreation settings will result in their rejection because they are viewed as different. This is not always the case. For example, Erwin and Guintini (2000) found that, in a structured inclusive environment such as preschool, children with and without disabilities could have shared, meaningful experiences. Much like a subculture, preschool classrooms often have rituals that foster a collective identity (e.g., circle time), which can result in recurring, positive social experiences. Buysse, Davis Goldman, and Skinner's (2002) conclusions support this notion: They found that typically developing children in the regular preschool classroom did not have more friends than their peers with disabilities had.

In a study of elementary school students, Rossiter and Horvath (1996) found that nondisabled children in integrated classes (i.e., those classrooms containing both children with and without disabilities) had more positive attitudes toward children with disabilities than did nondisabled children in nonintegrated classes (i.e., those classes without children with disabilities). In nonintegrated settings, children without disabilities do not get the opportunity to interact with children with disabilities and, consequently, label them as different (Davern, & Schnorr, 1991). These results suggest that nonintegrated settings are microsystems that restrain social behaviours between children with disabilities and children without disabilities. In the integrated classroom, which is perhaps a more socially inviting microsystem, students with disabilities were more likely to be viewed as fun, and nondisabled students were less likely to mention their disabilities (Davern & Schnorr, 1991). Palmer, Borthwick-Duffy, and Widaman (1998) found that mothers had little concern about their children who were in regular settings being mistreated or isolated; they viewed their children as being accepted. Hall (1994) examined the peer nominations of young children and, although the nominations varied, none of the children with developmental disabilities received the most negative nominations. In fact, one of the children with developmental disabilities was rated as the most popular child in class.

Similarly, Turnbull, Periera, and Blue-Banning (1999) described a case in which one child's alienation stopped once he/she entered a community school. On the other hand, children who are not socially included in the same contexts (i.e., microsystems) as their peers are often viewed as "visitors" to the class (Giangreco, Edelman, Cloninger, & Dennis, 1993). If individuals with disabilities are not included at an early age, they struggle throughout their school years to become accepted, but if they start school in a socially inclusive classroom, they begin their school career as an "insider" (Hall & Macgregor, 2000). This finding is in line with Bronfenbrenner's (1967) comments on mesosytems: Peer acceptance in the early years of school can foster peer acceptance in the higher grades.

In the teenage population, Lee, Soo, and Bak (2003) found that, according to adolescents without disabilities, the opportunity to spend time with students with disabilities was the most important contributing factor to friendship formation. Opportunity to form friendships in the microsystem of school could set up future social interactions in other environments out in the community (e.g., leisure settings), thus creating a socially inclusive mesosystem. Such contact could result in acquaintances becoming mutual friends and give rise to lasting relationships (Kennedy & Itkonen, 1994).

Though little research in this area has focussed on the peer acceptance of the adult population, some results do show evidence of peer acceptance in socially inclusive work environments, thus lending further credence to Hatch's (1993) notion of the social governance of a "work culture." Test et al. (1993) researched the social standings of employees with disabilities and found that co-workers were more comfortable with and accepting of persons with disabilities than the general population was. In addition, the co-workers also viewed the person with disabilities as more socially and vocationally competent. From the perspective of the persons with disabilities, 97.1% reported that they had friends at work and 32.3% reported that they spent time with their work friends outside of work (Test et al.). It seems that, according to these results, an accepting "work culture" and the opportunity to interact with co-workers with disabilities in the work microsystems increases social acceptance and fosters better social interactions.

In contrast to the findings of social acceptance of individuals with developmental disabilities, other studies have reported incidents of social rejection or isolation. Nabors (1997) found that, although the preschool children with disabilities did not receive negative nominations from their nondisabled peers, they still had less positive nominations and were not as readily accepted. Children without disabilities tended to receive higher overall ratings and were viewed as more preferred play partners than were their peers with disabilities (Guralnick, Connor, Hammond, Gottman, & Kinnish, 1995). Mothers of children with disabilities are often concerned about peer rejection even when there are positive interactions (Guralnick, 1995). In support of this concern, clinical observations have revealed that children with disabilities are sometimes described as *outsiders*, *lonely*, or *disruptive* (Piers & Schriebenman, 1997). In Strain's (1984) research, nondisabled preschool children preferred partners with disabilities who had higher IQs; they chose no child with an IQ below 42 as a friend. Though all play potential partners in this study had disabilities, there was a partiality towards those partners who were more similar to those rating them (i.e., the nondisabled children). Perhaps, as in Festinger's (1954) social comparison theory, the children without disabilities felt more competent when they interacted with peers more like them because the children with the less severe disabilities had more similar characteristics and experiences on which to base comparisons.

Similarly, Siperstein et al. (1997) found that elementary school students without disabilities more frequently nominated another nondisabled student as a person with whom they would like to spend time. The classes that showed the least rejection of their classmates with disabilities had the highest number of children with disabilities. It is notable that the students with disabilities in this context had a comparison group who were more similar to them. Also, parents of children in this age group reported disappointment in the number of play invitations that their children with developmental disabilities received (Geisthardt et al., 2002). These children appear to have been more accepted among other children with disabilities than they were among their nondisabled peers.

In high school, student membership and acceptance in the classroom often depend on affiliation with a peer subgroup (Schnorr, 1997). Unfortunately, many students with disabilities do not have this affiliation or the skills to gain membership into a subgroup. In fact, Zetlin and Murtaugh (1988) reported that nondisabled adolescents often have a more extensive network of friends than their peers with developmental disabilities. Lovitt, Plavins, and Cushing (1999) found that 15 out of 25 high school students with disabilities reported negative social experiences in school, including rejection and isolation. Relatedly, Cutts and Sigafoos (2001) found that most of the students placed in regular classrooms spent large portions of time without social interactions; and, when there were interactions, many of them were negative. Students with disabilities rarely had plans with their peers on the weekends or outside of the classroom (Zetlin & Murtaugh, 1988).

Green, Schleien, Mactavish, and Benepe (1995) found evidence of rejection of adults with developmental disabilities. They noted that if, these adults showed negative or aggressive behaviours, there were immediate negative perceptions of them, and social contact was discontinued. Furthermore, Rusch, Hughes, Johnson, and Minch (1991) found that, although co-workers were willing to take on several roles in the lives of their co-workers with developmental disabilities (e.g., trainer or evaluator), few would identify themselves as a friend of the person with a disability. The frequency of teasing, joking, and general conversations was lower with employees with developmental disabilities. Perhaps if the adults with disabilities had been socially included earlier, they would have had a social network from their younger years on which they could rely.

Types of Relationships for Persons with Disabilities

In school. A third approach to the study of social relationships for persons with disabilities is to examine the types of relationships in various settings and describe their characteristics. This research is often more descriptive in nature and strives to increase the understanding of specific interactions that take place in different contexts. Meyer (2001) studied the different types of social relationships that were operant in a socially inclusive elementary classroom. One relationship that he observed was the *ghost/guest* relationship in which the child is treated as a visitor rather than as part of the group. This can be the case for individuals with developmental disabilities, especially if they are only partially included. If children are segregated for even a portion of the day, they tend to feel rejected (Freeman & Kasari, 1998), thus suggesting that the segregated and inclusive settings are not interacting as a mesosystem in which success in one setting ensures success in another setting. If, however, the child is supported in socially inclusive settings and provided with supports that encourage social interactions, that child can enter the *just-another-student* relationship (Meyer, 2001). In this case all students were seen as members of the group and were fully included in all classroom activities equally. Sometimes, though, in the case of social inclusion, the peer relationship changes so that the student with a disability becomes the *inclusion child* (Meyer, 2001), and other students tend to be overprotective and have different expectations of the included child. Related to this relationship is Meyer's (2001) *I'll-help* relationship. Students without disabilities consistently act as helpers to the child with a disability, and the child with a disability is not expected to help anyone else. Although this type of relationship can provide the child with the physical or task-related support that he/she may need, it can also be viewed as a "mothering," "bossy," or "baby brother/baby sister" relationship (Hall, 1994; Strain, 1984). It is essential to have a classroom culture (macrosystem) that fosters independence while, at the same time, providing the appropriate individual supports.

Finally, Meyer (2001) identified two categories of friendships: regular friends and best friends. Best friends are considered friends forever. In regard to friendships during the school-age years, Guralnick et al. (2007) found that, even though the majority of their participants were male, most of the friends were female. It cannot be determined, however, whether children with disabilities choose friends of the opposite sex or whether females are more accepting and therefore better friends of children with developmental disabilities. In addition, the friends of the children with developmental disabilities were approximately 6-7 months younger than the focal children.

At work. As in the school setting, different types of social relationships can occur in socially inclusive work settings. Henderson and Argyle (1985) described three types of relationships that occur between persons with disabilities and their nondisabled co-workers: work acquaintances, work friends, and social friends. Work acquaintances meet each other through work tasks and have superficial or task-oriented relationships. Work friends, however, have more intimate interactions and can interact socially as well as through their work. On an even deeper level, social friends initially meet at work but carry their friendship beyond the workplace and meet at external events. Depending on the social atmosphere of the work culture, co-workers can assume many roles in the lives of persons with disabilities (Chadsey & Beyer, 2001; Hatch 1993), even as friends.

In segregated settings. To examine the social relationships that form in segregated environments, Diaz Moore (2000) focussed on the social relationships that existed in a special care unit for adults with disabilities and found three different types of friendships in addition to acquaintance relationships: congenial friendships, cliques, and confidantes. The congenial friendship, which results in resistance to acting-out behaviours that disturb the congeniality of the individual's interaction with peers, focuses on respect and keeping the interaction cordial. The clique centres on similarities to others, and it is therefore difficult for an outsider to become part of the "group." Confidantes have a relationship based on camaraderie; the individuals support each other emotionally and listen to each other's thoughts and feelings. According to Festinger (1954), these types of relationships are able to form because, in the segregated setting, the individuals compare themselves with someone who is similar to them, thus fostering feelings of social competence and self-concept that contribute to mutual, reciprocal interactions.

Role of the family. Family plays an important role in the lives of many individuals with disabilities. For many, family is a microsystem that supports them in their ventures in other settings (e.g., school, work, leisure activities), thus creating a socially inclusive mesosytem. Two studies (Day & Harry, 1999; Geisthardt et al., 2002) identified the importance of cousins as playmates for young children. Cousins are easily accessible as playmates and most often know the child with a disability from birth. In addition, siblings can play an important role in the social lives of individuals with disabilities. Not only can siblings serve as potential playmates, but they can also introduce their own friends to the individual with a disability, thus providing more potential playmates for their brother/sister (Geisthardt et al., 2002).

The topic that most frequently appeared in the family literature was the role of parents, especially mothers, in their children's social interactions. Some researchers have found positive social outcomes for those individuals with developmental disabilities whose parents actively initiate informal peer interactions for them (Bhavnagri & Parke, 1991; Ladd & Hart, 1992). Parents can assist in planning social events in which the individual with a disability will be successful (Keachie, 1997). Parental supervision is also key in ensuring that interactions between persons with disabilities and their friends are successful, especially at a young age. Without this support, social inclusion cannot be achieved. In many cases, however, this supervision is often focussed on the physical safety of the children rather than on their social interactions within each microsystem (Geisthardt et al., 2002).

Role of support staff. Many persons with developmental disabilities have support staff as active participants in their microsystems. Whether it be a teaching assistant during the school years, a job coach at work, or caregivers in their homes, these staff members often make significant contributions to the lives of persons with developmental disabilities. Test et al. (1993) found, in their study of socially inclusive workplaces, that job coaches provided many social supports to persons with disabilities. These supports included explaining schedules, talking about life, caring about their clients, providing reminders, obtaining special equipment, and introducing the person with disabilities to potential friends. If staff support and initiation of activities were reduced, then the person with a disability took part in fewer activities (Birenbaum & Re, 1979). Relatedly, Recchia and Lee (2004) found that positive relationships between children with disabilities and their support staff are a key element of successful social inclusion.

It is also important to note, however, that at times support staff relationships can move "beyond dichotomous caregiver/carereceiver labels to allow for the possibility of a different kid of relationship" (Pottie & Shumarah, 2004, p. 64). Sometimes individuals can form reciprocal friendships with their support staff. Some sceptics question whether this type of relationship can be considered a "true" friendship, but as Lutfiyya (1990) found, even when support staff moved away or were transferred to a different placement, the person with a developmental disability and the staff member often strengthened their ties to each other and made further efforts to maintain contact. Even when the caregiver/carereceiver relationship ends, sometimes the friendship that underlies that initial bond remains intact.

Summary and Conclusions

Inclusion advocates have argued that segregated microsystems unfavourably affect the social development of individuals with disabilities and that segregation itself acts as a subculture that is contradictory to the culture in which persons with disabilities are expected to function. Supporters of segregation, however, have demonstrated that social inclusion is not always achieved and placement in regular environments could be damaging to one's self-concept if the proper conditions are not present. With collaboration between educators (i.e., the schools) and policy makers (i.e., the government) who, as a mesosystem, value social inclusion, a powerful exosystem (i.e., external influence) can assist in the successful social inclusion of individuals with disabilities.

Though past research has focussed on the social experiences of persons with disabilities, gaps still remain in the exploration of this phenomenon. Many studies have focussed on one particular age group, but few have merged these clusters to examine social experiences across the lifespan. In addition, most social relationship research has been conducted on school-age groups, with little emphasis on social inclusion beyond the school years. Of the research that has focussed beyond the school years, few studies have examined social inclusion in leisure activities, often an important component of a person's life.

Another area of importance that many researchers in this field have overlooked is the perspective of individuals with disabilities. Most research on social inclusion has relied on the perspectives of peers, parents, teachers, employers, or other community members. Few studies have involved input from persons with disabilities themselves and, of those studies that have, the merit of these individuals' perspectives is often questioned. Additionally, in studies of parental perspectives, mothers are usually the sole information source, which thus ignores the different perspective that fathers may be able to offer.

In my dissertation I have attempted to fill in the gaps within the social inclusion literature. By focussing on six different participants, I was able to gain insight into the different social issues that persons of different ages may face. Also, I was able to add to the limited research on social inclusion outside of the school setting. I interviewed persons with developmental disabilities about their social experiences in various settings, and this approach allowed them to tell their own social stories and have a "voice" in the academic arena. In addition, I used archived data from the Inclusion Across the Lifespan project that I collected from parents, both mothers and fathers, to supplement the stories of social inclusion. I also included the perspectives of teachers and employers to gain a more complete picture and a deeper understanding of the participants' social lives.

CHAPTER 3: METHODOLOGY AND METHODS

Introduction

The purpose of this research was to investigate the social relationships of individuals with developmental disabilities in school, work, and leisure settings. I conducted in-depth interviews with key informants and present the findings as case studies. During the interviews I used arts-based techniques (i.e., participant-produced drawings) to assist the participants in articulating their social relationships. The following chapter describes each component in the research process, as well as several methodological and ethical considerations that I reflected upon throughout the research process.

The Context for This Study: Archived Data

This project is an extension of a larger project completed at the University of Alberta. The Inclusion Across the Lifespan project was a three-year study that explored the general experiences of persons with disabilities in school, work, and leisure settings (see Appendix A for more detailed information). I have used some of the interview data from this larger project as archived data for the current dissertation project and extracted and reanalyzed any relevant social data from the project for use in the case studies. A thematic analysis of the archived data provided an initial description of the social experiences of the participants and produced further ideas for my own additional interviews.

Within this dissertation, the term *participant* or *key participant* refers to the individuals with developmental disabilities, and the term *parent/guardian* refers to the family members of the individuals with disabilities who took part in this project. In addition, for the purposes of this project, the term *teacher/employer* is a broad description that includes such personnel as teachers, educational assistants, vice principals, employers, and job coaches (i.e., support personnel who accompany the individual with a disability to his/her workplace). I will use these terms in this way throughout the remainder of this dissertation.

Methodology: Multiple Case Study

This study used a sociological case study approach (Merriam, 2002) with a focus on the social relationships and the social institutions that persons with developmental disabilities experience. The participants with disabilities were the key participants in my research and took part in focused interviews where I used an arts based technique to help clarify understanding. The archived data from their teachers/employers provided a rich source of additional information.

According to Rhydwen (2002) and Merriam (1998), the most striking aspect of performing case study research is the richness and complexity that can be captured. This type of research can be distinguished from other types of inquiry in that it is more concrete and contextual, is developed by reader interpretation, and is based on a reference population (Merriam, 1998; Stake, 2006). Three assumptions underlie this type of methodology: (a) The context has an influence on social behaviour, (b) the subjectivity of the researcher is the only means of knowing (i.e., the researcher interprets the data based on his/her subjectivities and preunderstandings and presents his/her findings through that lens), and (c) trustworthiness is ensured through multiple perspectives and methods (Merriam, 2002).

In order to conduct a case study, one must first define the case that will be studied. A case must be a single entity with boundaries (Merriam, 1998). Huberman and Miles (1985) used the metaphor of a heart with a circle around it to describe this concept. The heart is the focus of the study (i.e., social relationships), and the circle defines the edges of the case that are not studied (i.e., the nonsocial experiences in the environments). Although all of the individuals (i.e., key participants, parents/guardians, and teachers/employers) involved in this research had had experiences beyond the scope of this study, they also had direct experience with the social settings involving the key participants. The school, work, and leisure settings provided boundaries for the case, and the individuals in each case acted as the key players within those environments.

To further guide the research process in this type of research, Yin (1994, 2003) recommended using a case study protocol. This protocol assisted in maintaining the focus of the study and provided a succinct representation of the cases under consideration. It contained the general rules and procedures that I followed, such as the ethical considerations, the strategies I used to maintain trustworthiness and rigor, and the questions that I asked. This does not, however, mean that I dogmatically outlined the questions that I asked the participants, but rather that I asked research questions that reflected the purpose of the actual inquiry. For example, in the current research these questions included the following:

1. What types of social relationships exist for individuals with disabilities in school, work, and leisure settings?
2. What do the participants say is the importance of these social relationships?
3. What role do these social relationships play in the key participants' lives?

4. How do the parents/guardians and teachers/employers view these social relationships?

Each individual interview began with an open ended statement: "Tell me about the people in your workplace/school/leisure setting," and I encouraged the participants to follow their own thoughts as the interviews progressed. I asked guiding questions only when the participants did not know how to continue and needed prompting.

Sample Criteria, Selection, Procedures, and Description

Sample Criteria and Selection

The reader is reminded that the participants from my sample were selected from the larger Inclusion Across the Lifespan project. In that study, 36 individuals described by their parents and teachers as having a mild-moderate developmental disability were chosen for participation. Among these participants, six age groups (i.e., 3-6, 7-12, 13-17, 18-30, 31-50, 51+ years old) were represented, with 5-7 individuals in each age group. From this larger sample, I chose the participants who were the most knowledgeable and articulate about the phenomenon being studied in my research (i.e., the social relationships of people with disabilities). More specifically, I selected one key participant from each of the six age groups. It is important to note that the individuals chosen for participation in my research had mild-moderate cognitive disabilities compounded by such disorders as Down Syndrome, High Functioning Autism, speech and language impairments, and emotional disabilities. The contexts each participant lived and worked in also varied from fully inclusive to segregated settings, with some variance in the degree of segregation (e.g., school pull-out programs).

In all instances except the youngest age group, the persons whom I deemed to be the most articulate about the key participants' social experiences were the key participants themselves. In the 3-6–year–old age group, however, the child herself was too young to effectively communicate her social experiences. Instead, I identified the mother as the key participant in this case study to gather descriptions of her daughter's social relationships. To achieve rich description in a qualitative inquiry, the most appropriate sample must first be chosen; thus, this type sampling was the best technique for this study (Merriam, 2002; Morse, Barret, Mayan, Olson, & Spiers, 2002).

Sampling Procedures

Following the sample selection, I approached prospective participants, asked them to participate in the current study, and explained that this work is a separate study from the one in which they were currently involved. I then provided consent forms and letters of information to each individual involved (see Appendix B). Before proceeding with the project, I received consent and answered any questions that the participants or parents/guardians had. Specific ethical and procedural issues with the consent process for this sample will be discussed in the Ethical Considerations section at the end of the chapter.

Introduction to the Researcher

As the primary data-collection instrument in this research project, I entered the research settings with my own pre-understandings and subjectivities. In the past I have worked as support personnel for many children and adults with disabilities. During this job opportunity I gained experience in a variety of settings, including preschool classrooms, sheltered workshops, community work placements, recreational settings, and sporting events. I was also able to learn about specific disorders (e.g., Down syndrome, autism spectrum disorder, fetal alcohol spectrum disorder, etc.) and the "system" (e.g., funding structures, disabilities policies, agency politics, etc.) with which individuals with disabilities and their families contend. It is my belief and understanding that inclusion is an essential component of a successful social life. Through networking within the community, individuals learn life skills and meet people who can assist them in reaching their personal goals.

I have worked in successful inclusive settings as well as unsuccessful inclusive settings and have the subjectivity to state that many settings that are claiming inclusivity are in fact very exclusive in nature. Many environments do not have supports in place to successfully include an individual with a disability. I entered the research situation with the assumptions that many professionals in the field of special education define inclusion as an issue of placement and that simply placing the person with a disability in an environment with his/her peers is often labelled inclusion. I believe that an individual can be placed in an environment with his/her nondisabled peers and still be excluded until the proper supports are offered. These supports are individual in nature and wholly dependent on the specific needs of the individual.

Finally, it is also my assumption and experience that inclusion provides two-way benefits. Not only does the individual with a disability benefit from the inclusion, but so do all those around him/her. Individuals with disabilities can act as role models for others who are facing challenges and can provide the same compassion and emotional support that other friends do. I believe that, although I was conducting research in the area of inclusion, it was important not to overlook the benefits of social inclusion to people without disabilities. I myself have experienced great personal gain through my contact with individuals with disabilities. Throughout the course of my work experiences I have formed friendships with numerous persons with disabilities, and these friendships have assisted me in learning how to cope more easily with my own challenges because I have role models who face challenges every day. In addition, I have had the opportunity to experience the compassion and sincerity that many persons with disabilities bring to their friendships. It has been my experience that many individuals with disabilities have an unconditional acceptance of others because they may have faced discrimination themselves.

In addition to my work experience, I have also experienced disability on a personal level. When I was a young child, my mother was diagnosed with severe depression that proved to be treatment resistant. Because of this mental illness, my mother was unable to continue working as an educator and was required to receive disability insurance. Though her disability was different from the disabilities that I have studied during my tenure as a graduate student, my experience of growing up with a mother with a psychological disability helped me to gain insight into the stigma surrounding many individuals with disabilities. I experienced firsthand the societal misconceptions about persons with disabilities and the challenges that these individuals face in trying to establish themselves as contributing members in their communities.

Another more recent personal experience with disability is related to a disorder with which I cope on a daily basis. For the past six years I have lived with chronic pain, and in September 2006 I was diagnosed with fibromyalgia. Although some may argue that this disorder is not typically defined as a disability, it is certainly disabling at times.

Throughout this ordeal I have come to better understand the frustration that can accompany physical limitations and societal misunderstandings. Moreover, I have experienced the isolation that can occur when others do not understand the disorder with which you are coping. Though this experience has been challenging, I am grateful for the increased insight into the lives of persons with disabilities. I have been better able to relate to the experiences of my participants during the interviews, and many of the participants seemed more prepared to open up to me when I shared some of my personal challenges with them.

During the Inclusion Across the Lifespan project I acted as the key research assistant. This position allowed me to gain access to the participants for two years prior to the start of my dissertation research. Learning about each participant assisted in focussing my research questions and choosing participants who would be the most appropriate as key participants in the case studies. Furthermore, previous contact with each participant helped me to build strong, trusting relationships that facilitated the arts-based interview process. The participants' familiarity with me made them feel that they could disclose personal information without fear of ramifications.

Introduction to Key Participants

Stephanie. Stephanie is a six-year-old kindergarten student with Down Syndrome. At the beginning of the Inclusion Across the Lifespan project she attended a regular community playschool in an urban setting, and at the end of the project she was attending a regular kindergarten class.

Stephanie was very sociabl during the interviews but had difficulty describing her experiences in detail. Like many six-year-olds, she would provide surface answers rather than in-depth descriptions. When I visited Stephanie at her home, she always greeted me with excitement and was happy to show me her newest toys. She would want to be interviewed in her playroom so that she could play with her toys during our discussions. At times I would have to take a break to play with Stephanie before asking the next question to ensure that she was willing to focus on her answers. Because Stephanie would sometimes talk about topics that were not related to the questions or would make up stories, her mother would assist me by prompting Stephanie or adding information to increase my understanding.

Stephanie's mother, Nancy, was eager to participate in this project and described in detail many of her daughter's social experiences and relationships. Moreover, she was able to elaborate on many of Stephanie's interview answers. Nancy is a stay-at-home mother who has dedicated much of her time to educating herself about disabilities so that she can better facilitate her daughter's inclusion in the community. She kept in close contact with me throughout the research process through phone calls and was always interested in my latest findings. She also provided me with contact information for speakers she heard at numerous inclusion conferences.

Following the interview with Nancy, we had an informal conversation about inclusion and her thoughts on her experiences with inclusion. She was also interested to hear my opinions on some topics and was happy to hear about my own experiences with persons with disabilities.

In addition to gaining Nancy's perspective, I also interviewed Stephanie's teacher in the Inclusion Across the Lifespan project; she was able to provide supplementary information on Stephanie's social experiences and challenges. I interviewed the teacher after school at her home, and she was, at times, hesitant to provide information until I assured her that Nancy had consented to the interview. She was more open about her general classroom practices than she was about specific interactions with Stephanie.

Kurtis. Kurtis is a 12-year-old boy who has been diagnosed with high-functioning autism. He attends Grade 7 in his community school in a rural setting and is a participant in what could best be described as a pull-out program. He attends class in the regular classroom but receives instruction in the special education classroom for certain subjects (e.g., mathematics). Kurtis also has an educational assistant who works with him for the majority of his time at school, although recently he has spent fewer hours with his assistant and is expected to participate independently in many school activities. During this study Kurtis made the transition from elementary into junior high school, which was a large transition for him, and he needed a great deal of support during this time.

Kurtis lives on a farm with both of his parents, who are farmers, and his two sisters (one older and one younger sister). Both of Kurtis' parents took part in the interviews for the Inclusion Across the Lifespan project and were very open and honest about their negative and positive experiences with Kurtis. They often used humour to communicate their perspectives and were comfortable in openly stating their opinions when they did not agree with school policies or practices.

In addition, I also interviewed Kurtis' teacher and teaching assistant as part of the Inclusion Across the Lifespan study. These interviews took place during school time and, therefore, had to be more structured because of the time limitation. Both the teacher and the teaching assistant answered the questions in a clear and concise manner and offered their phone numbers for any additional information that I might need. No further follow-up was needed with the educators because they provided adequate information during the interviews.

For this project, I interviewed Kurtis at his school because his mom thought he would be more focussed early in the day rather than after school. Kurtis took part in the interview independently but required much prompting from me because he was having, as his teaching assistant described it, “a bad day” and would wander off topic easily. Kurtis was pulled out of class to take part in the interview, and this seemed to frustrate him. During the interview he kept referring to the project on which he was supposed to be working in class at that time. He was worried that he would not finish the assignment, and I had to reassure him several times during the interview and take breaks to talk about his school project before he would answer the interview questions.

When asked to produce art that represented his social experiences, Kurtis was hesitant in his drawing and refused to draw a picture of his classroom. He told me that he could not remember his classroom, so he could not draw it. Instead, he drew a picture of himself and was able to refer to his own clothing as a guideline to what he should draw. This introduction helped Kurtis to gain confidence in his drawing, and, following his self-portrait, he was prepared to draw more pictures. He would become easily frustrated if I probed for information too much, and I had to quickly find a balance between using probes and leaving some questions unanswered.

Nicole. Nicole is a 15-year-old Grade 10 student. During this project Nicole transitioned from junior high to high school. She enjoyed this transition because she found junior high very challenging socially. Nicole’s disability was unspecified and diagnosed only as a global developmental disability.

Nicole had been very ill as a young child and spent most of her first six years in a hospital setting. Currently, Nicole lives with her mom and her older brother in a group of townhouses set up as a small community within the city. During the Inclusion Across the Lifespan project, I interviewed Nicole's mother twice. She approached each interview in an outgoing manner and was willing to openly discuss topics that would, at times, become very emotional for her. She stated that she felt comfortable in talking to me during the interviews and that it felt good to speak with someone who was willing to listen. Nicole has limited contact with her father and prefers not to spend time with him. There has been a great deal of tension between Nicole and her father since her parents separated when she was a young child.

Prior to attending her local suburban school, Nicole attended an urban Christian school. She is a member of a special education class and has been in special education settings for most of her schooling. Both Nicole's teacher and teaching assistant participated in the Inclusion Across the Lifespan interviews, and their perspectives allowed me to understand Nicole's social functioning in the school environment because they reported that she was struggling more in school than she was at home. The teacher and teacher aide discussed Nicole's social relationships with both compassion and frustration. They were excited that her social life was being addressed because it was their biggest concern for Nicole.

At the time of the interview for this project, Nicole had become familiar with me through the Inclusion Across the Lifespan project. Although she was still shy during the interview for this project, she had learned to trust me and was excited to tell me about her accomplishments since my last visit. Nicole's mom was present during the interviews, as

Nicole had requested. Her mom's presence seemed to ease any anxiety that she felt when she could not think of an answer to a question because she could look to her mom for prompting and support. The art-making process during this interview also assisted Nicole in more thoroughly answering the questions because she has a passion for art. Drawing and painting are talents of which Nicole is very proud and, when I asked her to draw pictures of her social experiences, she did so with great care. Nicole concentrated a great deal while drawing her pictures and would not speak during the art-making process. I quietly spoke to Nicole's mom while Nicole took her time to complete her artwork and continued with the interview when she had completed her drawing. Following each drawing, Nicole was able to tell a story about each picture, which allowed me to become further immersed in her social experiences

Erica. Erica is a 28-year-old with Williams syndrome. The main difficulty that Erica has faced regarding her disability is a speech delay. As a young child Erica received intensive speech therapy, which resulted in an ability to express herself well. Erica is a college graduate, having received her diploma in early childhood education. She was supported through a disabilities support program and received accommodations and modifications to meet her educational needs.

Erica is a member of a committee to advocate for the needs of postsecondary students with disabilities. For leisure, Erica is highly involved with Special Olympics and an outing group for individuals with developmental disabilities. Erica lives with her mom and also has contact with her older brother. Her father passed away a few years before this project began, but she still talks frequently of the time she spent with him while he was alive.

Erica's mom, Susan, participated in the Inclusion Across the Lifespan project and was eager to assist me in building a relationship with her daughter. During my first visit to Erica's home, Susan invited me for lunch so that she and Erica could get to know me before the formal interviews began. Susan talked candidly during her interview about the successes and challenges that Erica has faced throughout her lifetime. She also discussed the emotional impact that many occurrences in their lives have had on them and how they have shaped Erica's experience.

Currently, Erica works at two part-time jobs, one as a support staff member at a day care and the other as a playgroup organizer and office assistant in a program for preschool children with disabilities. She works two days per week at the playschool and one day per week at the disabilities program. During the Inclusion Across the Lifespan project I interviewed two of Erica's supervisors from the program for preschool children with disabilities. In addition, they asked Erica to join the interview so that she would be able to state her opinion about her work situation. Her employers were conscious of including Erica's perspectives in our discussions and stated that hearing her reports would assist them in becoming better employers.

During the interview for this project, I met Erica at her home. She greeted me with enthusiasm and was interested to hear what I had been doing since our last encounter. We built an easy rapport because we are the same age and share many common interests. Erica enjoyed spending the first few minutes of the interview getting reacquainted and "caught up" with each other. In addition, I also used to work for the same company that employs Erica, so we could easily relate to each other's work experiences.

Erica enjoyed creating art during our interview and used several different mediums such as paint, pencil crayons, and markers to complete her drawings. She talked about her experiences while creating the art and would discuss the pictures in detail as she drew them. Erica was careful to add detail to the pictures and explain the significance of each person and object. Following the interview, Erica was excited to show her mom her artwork and tell her some of the stories that she had shared with me.

Bonnie. Bonnie is a 42-year-old day care employee. She also completed her early childhood education diploma but did not receive any disability specific supports. Instead, Bonnie relied on tutors to assist her during her postsecondary education.

Bonnie has worked at the day care for more than 10 years, and to supplement her income she also works as a porter during sporting events. As a child, Bonnie attended a school for persons with mental handicaps. She has a mild cognitive disability as well as a speech delay. With years of intensive speech therapy, Bonnie is now able to carry on conversations with relative ease and only on occasion has difficulty pronouncing certain words. Bonnie is married and lives in an apartment complex with her husband, Norm. Norm participated in the Inclusion Across the Lifespan project as Bonnie's family member and met me in the research office to complete the interview because he was going to be nearby for other appointments. He needed little prompting to talk about Bonnie and did so with great passion. He enjoyed telling stories about their lives together and was proud of Bonnie's perseverance through difficult times. Norm is a very social person and enjoys visiting with people.

Bonnie's employee, Eva, was interviewed once during the Inclusion Across the Lifespan project. This interview took place at the daycare where Bonnie works but, unfortunately, the background noise interfered with the recording; I could not review or transcribe the interview because it was almost completely inaudible. I attempted to schedule a second interview with Eva but was unable to find a time in which she was available. Eva has a very busy schedule and was not sure whether she would be able to take part in a second interview.

Bonnie was proud to be part of both this project and the Inclusion Across the Lifespan study. Between visits with her, she would maintain contact with me through phone calls and e-mail; she was anxious to know when my next visit would be and wanted me to visit her in her work environment. The interview took place at Bonnie's home following an informal visit to her workplace so that she could show me what she did at her job. Bonnie seemed to want to give the "right answers" during the interview and, even though she seemed comfortable with me as the interviewer, she displayed a need to please me. I encouraged her often to assure her that I was pleased with any information that she gave me.

During the art-making process, Bonnie was hesitant because she lacked confidence in her drawing ability, but with encouragement she was able to draw simple characters and formations. These drawings allowed her to have a focus for our discussion and cued her on certain "happenings" in her work and leisure settings. Following the art process, I asked Bonnie follow-up questions about her social relationships; she was able to answer these with more confidence because we had just discussed specific examples of her social experiences during the art-making process.

Lyle. Lyle is a 63-year-old man with a cognitive delay as well as a history of mental illness. Lyle grew up in another province but moved to his current home after his mother passed away. This was a very difficult transition for him, both emotionally and physically. He now lives in an apartment complex in an urban setting.

Lyle does not have paid employment, but he volunteers both formally and informally for the advocacy agency that supports him. During the Inclusion Across the Lifespan study, one of the support staff at this agency met with the research team and discussed Lyle's role as a volunteer in their organization. Because of their limited contact with Lyle, they were unable to provide in-depth information regarding his social relationships but were able to cue us as to possible questions that we could ask Lyle for further clarification.

Lyle has one sister, Doris, who lives in the same city, and he relies on her for a great deal of support. Doris was interviewed as part of the Inclusion Across the Lifespan study. She was concerned that she was not going to be able to provide addition information but, after several minutes of discussion, it became clear that she had much to add to Lyle's story. She is a very quiet person with a gentle nature and, therefore I had to build rapport before delving into more emotional topics such as Lyle's social challenges. Doris expressed some frustration with Lyle because she felt that she was alone in supporting him. She did, however, state that Lyle had numerous friends with disabilities with whom he spent time.

At the beginning of this study Lyle was living in an assisted-living complex with a specialized program for individuals with disabilities. The following year, however, he expressed a desire to live more independently and moved into his own apartment. Lyle is his own guardian and trustee and makes most of his decisions independently. During the interview for this project Lyle stated that he enjoyed having me at his place for a visit. He said that he felt comfortable in talking to me and that he liked to tell me about his life.

When I asked him to draw some pictures during the interview, Lyle became very anxious but said that he would try. I asked him to draw a picture of his volunteer workplace and, at that point, he was silent and appeared to become tense. He sat for a couple of minutes and then looked up and said, "I don't know." At this point I abandoned the arts-based techniques and conducted a regular open-ended interview. Lyle relaxed after the art supplies were put away and was able to complete the rest of the interview in comfort.

Methods

Analysis of Archived Data

As mentioned previously, I extracted and reanalyzed all of the data from the Inclusion Across the Lifespan project pertaining to the social lives of the six key participants. To organize the data into common themes, I used the qualitative data analysis package NUDiST (N6). I downloaded each data file into the N6 program and coded them into broad themes and narrower subthemes. Further description of this analysis will be included in the Data Analysis section of this chapter.

Interview Procedures and Techniques

Conducting the qualitative interviews. Following the analysis of the archived data, I conducted additional supplementary interviews with the key participants. I used open-ended questions to give each person the freedom to express his/her experiences, subjectivities, preunderstandings, concerns, and opinions (Seidman, 1991; see Appendix C for sample interview questions). At times, I asked the questions in a more direct, structured manner depending on the expressive and receptive communication abilities of the participants. In one case (i.e., Stephanie), I chose to interview the mother, Nancy. Because of her young age, Stephanie was unable to provide in-depth information on her social experiences. Instead, I analyzed her data and included them where possible as a secondary source of information in the case study.

Use of participant-produced drawings. Because, for some persons with disabilities, emotions, attitudes, and beliefs are often hard concepts to articulate, I augmented the interviews with the key participants with an art-based technique (i.e., participant-produced drawings; Fox & Geichman, 2001; Kearney & Hyle, 2004; McNiff, 2004). In this project it was important that I ask questions that referred to specific activities or events to enable the participants to answer them successfully (Finlay & Lyons, 2001). This approach helped to make the concept of social relationships more concrete because it gave them another medium through which to evoke and describe their memories.

I asked the participants to draw a picture of their classroom or workplace, their favourite leisure setting, and a friend (see Appendix C for detailed instructions). I provided numerous art supplies (e.g., pencils, pencil crayons, markers, wax crayons, and paint) to allow the participants to explore different mediums and to choose one that was the most comfortable to them. In addition, I gave the participants different sizes of paper to allow them to draw as much or as little as they wanted. The participant-produced drawings gave them a starting point from which the discussion flowed. All participants, except for Stephanie and Lyle, created drawings. In Stephanie's case, I interviewed her mother as the primary data source; therefore, I did not need participant-produced drawings. As stated in the participant description, the request to draw resulted in a great deal of anxiety for Lyle; I gave him the opportunity to refuse the art process, and he took part in a regular open-ended interview instead. I relied on his verbal representations of his social relationships rather than his artistic expressions. Sometimes individuals do not feel confident in their ability to produce a piece of art and are afraid of looking foolish. For detail-oriented persons, art can be stressful because it does not allow them the accuracy and precision that they would like (Kearney & Hyle, 2004). A participant must never be coerced into producing art.

In all cases in which the participants produced art, I included the discussions prompted by the drawings in the transcripts and coded them alongside the rest of the transcript data. I did no individual interpretation or analysis on the art itself, but used it only as a catalyst to foster deeper conversations. I could explore the art's meaning only through interactions between me and the artist. In some instances I have incorporated examples of art into the case studies to illustrate a concept that a participant described.

Important attributes of the interviewer. According to Seidman (1991), listening is the most important skill in interviewing. Listening carefully can help the researcher to determine the difference between the participant's public voice and personal voice. A public voice includes the characteristics and conversations that a participant uses to represent him-/herself in the "outside world," whereas a private voice is the voice that a person uses internally and with those close to him/her. Often, because the participants in a study want to represent themselves in a positive light, they will present only their public voice in an interview. Through my work on the Inclusion Across the Lifespan project, I built rapport with the participants that, I believe, allowed them to feel comfortable with me during the interviews and helped them to be more open in their descriptions. Furthermore, I have extensive experience in working with persons with developmental disabilities, which helped to facilitate open communication with the key participants during the interview process.

Another desirable attribute of a researcher in an interview is genuineness (Seidman, 1991). There is a risk to all interviews (e.g., the participant may share things that he/she did not intend to share), but a genuine relationship can reduce the feeling of risk for both parties because trust can be built as the relationship grows. I was genuine in my approach to this research because of my continued advocacy for the rights of persons with disabilities. In addition to being genuine, the interviewer must remain open and committed to the participant during an interview. I displayed this commitment to the participants during my work as a research assistant in the Inclusion Across the Lifespan project as well as through the completion of this project. My contact with the participants extended over a three-year period.

Location of the interviews. Sometimes allowing the participant to choose the location of the interview is the best approach (Herzog, 2005). This choice is not based solely on convenience, but also allows the participant to have some input during the research process. Sometimes participants do not want the interviewer to go to their homes, but want to meet in a neutral location that frees them from the responsibility of having to act as a host (Herzog). In the current research I allowed the participants to choose the location of their interview provided that it had enough privacy to conduct such an inquiry. In all cases the key participants chose to have the interview take place in their homes, thus verifying Herzog's claim that the home is often the best interview setting.

On occasion, the interviews for this project would become highly emotional. For some of the participants, past social experiences brought negative interactions and challenges. For some, discussions of the negative aspects of their social experiences caused them to react with sadness, anger, frustration, or nervousness. In discussing experiences such as bullying, rejection, or prior institutionalization, it was important that I ensure that the interview take place in an emotionally "safe" location. I drew this conclusion based on my experiences and some of the emotional reactions that I witnessed during the interviews for the Inclusion Across the Lifespan project. Herzog (2005) suggested that any highly emotional interviews should take place in the participants' homes, which allows them to feel comfortable and provides a feeling of intimacy. The home places the participant in the context of the family and the community and allows the interviewer to gain a perspective of the participant's home life.

The guiding nature of interviews and the use of follow-ups. Interviewing is much like the hermeneutic spiral (Packer & Addison, 1989) in which a continuous analysis occurs during and after the interviews, and information that is gathered in one interview often provides direction for the next interview. The backward arc on the hermeneutic circle (Packer & Addison, 1989) also represents this continual analysis because a researcher must go back to clarify contradictions and gaps that may exist following the first interview. Follow-up interviews or conversations allow the researcher the opportunity to investigate such misunderstandings or omissions. During my data collection, I maintained open contact with the participants and their families. If I needed additional information, I was able to contact the participants or their parents/guardians via telephone or, in some cases, e-mail. In most instances I followed up the key participants interviews with a phone call following the transcription of the data. The phone conversations were often fairly short (i.e., 5-10 minutes) but allowed me the opportunity to clarify any misunderstandings and gather any additional details that I needed. If the key participant was unable to answer the clarifying questions, the parent/guardian would often provide the appropriate information. In one instance (i.e., Bonnie), the participant initiated regular e-mail contact, and we exchanged e-mail one or two times per month which, thus allowed me to gain further information and ask follow-up questions.

Special considerations in interviewing children and other vulnerable populations. In my project some of the participants might be considered vulnerable; therefore, it was important that I consider Ellis's (1998) guidelines for interviewing vulnerable individuals; namely, children. In this project three children aged 6, 12, and 15 acted as key participants. I have described each of these children previously in this chapter. On occasion, children may feel intimidated by the research situation, be shy or embarrassed, and feel unsure about what is expected of them (Fabian, 1996). It is important for a researcher to familiarize him-/herself with the child and build rapport before asking any interview questions. Because of my role in the Inclusion Across the Lifespan project and my previous contact with the participants, I readily built rapport with each participant. I made the first contact through the parents/guardians to ask them to remind the child of past interviews and discuss any concerns that they might have about the research process. I also found it very important to describe the purpose of the visit to the child in language that he/she could understand. For example, before each interview I reminded the child of the purpose of my being there: "I am here to talk to you about your school and your friends. Just tell me whatever you want to and, if you don't know the answer, say, 'I don't know.' Okay?" It is important to set some ground rules for the interview process so that the child knows what to expect. Many children, especially those with developmental disabilities, respond better to structured situations.

To further increase the comfort of the child, it was also important that I sit at the same level as some of the children (Cameron, 2005; Fabian, 1996). Sitting in adult chairs is often uncomfortable for a child and does not allow freedom of movement. Accordingly, at times I conducted the interviews sitting on the floor with the children. In Stephanie's case, she enjoyed interacting through her toys. To aid in this desire, I would sit on the floor or in an area in which she could access her toys. This was a more informal setting and allowed her to move around and demonstrate her thoughts through play or actions.

Ellis (1998) suggested that interview questions for children should be aimed at evoking memories, which are more concrete than opinions or feelings. Additionally, children should be gently guided toward memories that they would like to talk about, and it is important to ask the questions in appropriate language that they understand. It is also important to be organized and carefully prepare the questions that the child will be asked. Wording is critical in interviews, and a researcher should avoid large words that may sound as though he/she is "talking down" to the child (Cameron, 2005). Cameron even suggested preparing a list of appropriate prompts to evoke children's memories. In my experience, children are susceptible to being led by interjections such as "Yes" or "That's right." Instead, I used neutral prompts (e.g., "I see," "Tell me more," "Oh, really?")

during the interview processes to deflect the children from searching for the "right" answers (Cameron, 2005).

Many individuals with developmental disabilities, as was the case in my research, have difficulties with communication, and this was evident in my interviews with some of the key participants in this study. The difficulties included understanding grammatical structures, designing utterances appropriate to the situation, and understanding abstract concepts (Finlay & Lyons, 2001). In an attempt to to ensure effective communication, I familiarized myself with them by spending time talking to them prior to the formal interview. This familiarization and previous contact helped me to understand the language that the participants used and reduced the need for a translator. It was, however, sometimes necessary to have a significant other present to assist in translating the language. For example, Stephanie's mother was present to assist Stephanie in understanding the questions and to assist me in understanding Stephanie's spoken language. Because she did not always understand the language that I was using during the interview, her mother would reword the question using language that she knew Stephanie would understand. In addition, Stephanie's disability (i.e., Down syndrome) caused her to have difficulty in forming some words and, because her mother was familiar with her language style, she was able to help translate Stephanie's answers. Kurtis had no difficulty forming speech but did at times have a hard time organizing his thoughts into clear answers. His parents sat in on the interview to prompt Kurtis with language that was familiar to him and to help him to form his ideas into sentences that I would understand. Each time his parents would help him organize his answer, he would state whether that is what he wanted to say or not. Nicole was able to comprehend and answer the questions that I asked but wanted her mother to be present during the interview to give her confidence. Her mom's presence helped her to answer the questions without hesitation because she knew that her mom was there to help if she needed her.

Sometimes in qualitative research a participant's response does not seem appropriate to the questions being asked which, thus leads the researcher to assume that the participant did not understand the question when, in reality, he/she may still be trying to answer a previous question. If the participants' answers do not match the questions, the interview may be moving too quickly for them, and the researcher can try to slow the pace. I used this pacing strategy in this research as required.

Another communication dilemma is that definitions of certain concepts may have different meanings for this population. For example, people with developmental disabilities may define *friend* in a more general way than I as a researcher would. I had to specifically ask the participants, how they defined terms such as *friend* and *social relationship* so that I could understand whether the social relationships and the labels that they placed on these relationships meant the same to them as they did to me.

The interview process could, at times, be long and exhausting, and because some of the participants tired easily, we sometimes needed to take breaks. Accordingly, I gave the participants the opportunity to split the session into two or more sessions so that they did not feel rushed through the questions. Sometimes they just needed to be allowed to talk about a topic of their choice before we returned to the topic of social relationships. Flexibility is an absolute must in interviewing special populations.

Data Analysis

Process

Analysis of data in qualitative research is carried out in conjunction with data collection to allow the researcher the opportunity to collect more data as needed (Merriam, 2002). If analysis is not done in conjunction with data collection, a researcher runs the risk of producing hundreds of pages of transcripts and observations with no benchmarks or indicators to indicate the next step to take. In my experience, each interview helped to guide the next and, as I conducted the analysis, the questions that needed to be asked next were illuminated.

An examination of the interview context needs to be included in the analysis of the interviews because the context is the framework by which the story is bounded. I will describe each interview context in detail at the beginning of each case study. Additionally, it is important to include a description of my biases. Reporting my subjectivities and preunderstandings, as done earlier in this chapter, allows the reader to better understand the lens through which I interpreted the data.

Thematic Analysis

In summarizing the data in a case study, the researcher must usually synthesize the stories and experiences to clearly represent the phenomenon. Constructing themes makes the data less ambiguous and can help to construct the stories (Van Manen, 1997). Themes are ideas of a unified and holistic meaning (Van Manen). They are often beneath the surface and emerge from the data (i.e., they are not always apparent until the researcher becomes familiar with the data). To identify a theme, a researcher must first detect patterns and bring together many components or fragments of ideas and experiences (De Santis & Urgarriza, 2000). An idea must fit specific criteria to be identified as a theme. For example, a theme must emerge from the data, be extracted or inferred directly from the data, recur as a variety of experiences or behaviours, and be discovered at multiple levels of the analysis.

In this study I coded each interview transcript using the NUDiST Qualitative Data Analysis package (N6) to assist in identifying commonalities and differences. My analysis and subsequent identification of themes occurred both within and across cases (e.g., what were the differences in perceptions across cases?), as Stake (2006) outlined in his description of multicase analysis. Although the concept may seem straightforward, Marshall (2002) cautioned that researchers should never think of coding as a one-step process because it involves multiple steps that may include revising, moving, or deleting codes throughout the process. This process became apparent in this dissertation work as I coded and recoded data in my search for understanding.

Role of the Researcher

During data analysis a researcher must be able to recognize which data are significant and have the ability to piece facts together into categories. This does not have to be done alone, however. An inquirer can ask informants questions about the data to clarify and check for accuracy of the analysis. Following each interview with the key participants, I had an open-ended conversation with them to allow me to ask for further clarification as well as to allow the participants to ask questions. If participants are given the opportunity to provide input into the interpretation, they do not feel left out or violated (Smith, 1991). In addition, the parents/guardians were often present at the end of each interview, and I frequently participated in informal discussions with them as well.

Furthermore, I needed to be careful that I kept preexisting contemporary theories on the research subject and my previous knowledge and experience separate from the data to ensure that previous knowledge would not interfere with the analysis (Morse, 1994). However, Smith (1993) argued that, to understand others, I, as the researcher, had to interpret the expressions and activities in an already existing knowledge base. Background knowledge and theory are crucial to the interpretation of qualitative work, but I had to be conscious of their role in the interpretation. My previous engagement with the participants resulted in greater knowledge of the accounts that they described and helped me to achieve rich descriptions of their experiences. I had been engaged with the participants of the Inclusion Across the Lifespan Project for over three years and had built close relationships with each family, which allowed me to immerse myself in the experiences of the key participants.

Part of this submersion in the research process also included research collaboration. Collaboration with other groups can be used to validate and interpret the data, and peer examination is often an important part of ensuring this collaboration. Peers can discuss their findings with each other and the plausibility of such findings (Merriam, 1995). During my doctoral work, I had close contact with a student from the University of Prince Edward Island, as well as the research team located at the University of Alberta who also worked on the Inclusion Across the Lifespan project. Throughout the project we collaborated to assist each other with interpreting and writing the findings for our dissertations and theses.

Trustworthiness and the Assurance of Rigor

Trustworthiness is a measure of how well a researcher performs the task that he/she set out to accomplish (Lincoln & Guba, 1985). For a research project to be deemed trustworthy, there must be a fair and credible representation of the data. Furthermore, the study must also be rigorous to ensure that the findings can be trusted and believed (Merriam, 1995). I used several methods in the current study to ensure trustworthiness and rigor and will describe them in detail in the following sections.

Representative Data

What is most important in qualitative research is the representativeness of the data (Merriam, 1995); that is, how dependably and consistently the data describe the experiences within that context. Triangulation (i.e., the use of multiple methods or sources) can assist with this representation and the exploration of any inconsistencies in the findings (e.g., if the participant states something different from his/her parent; Daniel & Onwuegbuzie, 2002). In my exploration of social relationships I triangulated the data by using interview data from three different perspectives: the key participants, the parents/guardians, and the teachers/employers, where applicable. I included both the archived data from the Inclusion Across the Lifespan project and my arts-based interviews with the participants to ensure that I represented all three perspectives.

An additional consideration in this type of inquiry is the "fair" representation of a person's story. In most qualitative research situations the researcher has more data than he/she can ever use and can be overwhelmed by the quantity of the data; therefore, a researcher must always acknowledge that a case study represents only part of a story and that it is impossible to include every part of the story within the case study (Rhydwen, 2002). To claim to tell the whole story would be to misrepresent the participants and their perspectives.

One tool that is often used to ensure the representativeness of qualitative data is member checks; that is, the participants are provided with the tentative interpretations of the data as well as the hard copy of the data themselves and are asked whether the data "ring true" to them. This technique proved difficult to include in this research. Because of their disabilities, the participants had limited reading ability and were unable to review a written transcript effectively. Given financial and time constraints, it was impossible to review the transcripts verbally with each participant. In addition, some participants had a poor memory and did not always remember what we had discussed in previous interviews. To alleviate this problem, immediately following each interview I had an open conversation in which I asked clarifying questions, and each participant helped me to understand any misconceptions that I might have had. I also found this to be the best approach to use with the parents and teachers/employers because, many of them were too busy to review lengthy documents.

Rich, Thick Description

Rich, thick description refers to getting below the surface to the most enigmatic aspect of the phenomenon (Eisner, 1998); it is essential in demonstrating the trustworthiness and representativeness of the data. Each finding in a qualitative inquiry must be supported by raw data which, in many cases takes the form of quotations. Additionally, the presentation of findings must include a thorough description of the context, the interactions within the context, and the researcher's interpretations based on these interactions. Thus, my results section describes each interview context and includes quotations from parts of my conversations with the participants and my personal analysis of these discussions.

Ethical Considerations

[illegible]powering the Participants

There is almost always an asymmetry of power in any interview interaction, and the power is usually on the side of the researcher (Vincent & Warren, 2001). Often the researcher is viewed as an important person, which can be intimidating for many participants, particularly those with disabilities. A researcher needs to try to rectify this power struggle by finding some way to empower the participants, such as choosing the location for the interview, as I described in the interview procedures. I allowed all of the participants to choose the location that best suited them and gave them the greatest sense of comfort. Moreover, I also reminded the participants that they could stop the interview at any time and that we could take a break during the interview if they felt that they needed to do so. In the cases of Kurtis and Nicole, allowing them to have their family members present during the interview helped to empower them by fostering the feeling of security from having familiar people to ask for help if they became uncomfortable.

Role Conflict

In my research I felt that it was important to maintain clear boundaries during the interviews to avoid mixing roles because, in many research projects, the researcher faces a potential role conflict (Johnson & Macleod Clarke, 2003). I had to be conscious not to fall into the role of support personnel; furthermore, I felt it necessary to draw an appropriate distinction between *friend* and *data collector*. At times the key participants would demonstrate a desire to develop a friendship and want to take part in recreational activities with me. Though many qualitative researchers may view this as a desirable situation, I felt it necessary to maintain this distinction to avoid confusing the participants. In these instances I had to take care to maintain professional boundaries. Persons with disabilities often have many individuals who enter their lives for a short period of time and, if they view these individuals as their friends, they may feel rejected when this person is no longer a part of their life. With the boundary of *researcher* set out from the beginning, the participants were able to understand that I would be present for only a short period of time and would no longer have contact with them upon completion of the project. In addition, maintaining a professional boundary allowed the participants to refuse to answer any questions without feeling that they would disappoint me personally. If the participants showed a desire to take part in recreational activities with me, I would simply thank them for the invitation and explain that my job did not allow me to have personal relationships with my participants. This explanation allowed me to establish appropriate boundaries while still allowing friendly interactions during the interview process.

Informed Consent

The participants in any study must enter a study voluntarily with a full understanding of the obligations and potential consequences of the study. However, persons with developmental disabilities may feel obliged to be interviewed because of pressure that they feel from outside sources such as their parents (Johnson & Macleod Clarke, 2003). Also, the thought of having a sympathetic listener to hear their stories is seductive and may influence them to participate without being fully aware of the ramifications of the research process (Vincent & Warren, 2001). Ethically, all research involving human participants requires that all participants understand and consent to participation in the research process. Several of the participants in this study were under the legal guardianship of another person who needed to provide consent for their participation in this study. This sometimes resulted in adults with disabilities being volunteered by their guardians which, thus, resulted in a lack of understanding of what the project was and what their participation meant. In this study verbal communication between the participants and me became extremely important. I asked all adult participants to sign consent forms in addition to the consent forms that their guardians had signed. In addition, before proceeding with the interviews, I also verbally explained the study to each participant:

> I am here today to talk to you about your life in your community. I will ask you questions about what you like to do, where you work/go to school, your friends, and your family. You tell me whatever you want to tell me. There is no right answer. If you don't want to answer a question, just tell me. If you want to quit the interview at any time, just let me know. Okay? Do you have any questions?

Following this statement, I asked whether they still wanted to participate and answered any questions that they had. None of the participants had questions about the project upon giving their consent. Kurtis seemed to become uncomfortable during the interview, and I reviewed what the interview was about and asked him if he wanted to continue. He stated that he did want to continue but that he wanted to be done soon. Lyle wanted to speak with his sister before he consented to the interview. I gave him a copy of the consent form for his sister to review and followed up with a phone call the next day. After speaking with his sister, Lyle decided to continue with the project. In all other cases I encountered no unusual circumstances involving informed consent, but I was sure to revisit the issue several times with each participant.

Privacy and Confidentiality

Related to the issue of informed consent is the fact that guardians have a right to sit in on interviews or to request the transcripts of interviews. Although this is a parental right, it could, in many circumstances, infringe on the confidentiality of the interviews. In many studies sensitive topics are discussed, and individuals with a disability may not want their family members to hear their thoughts or feelings. In my research I explained the importance of privacy to the guardians and assured them that I would notify them if any important issues arose (e.g., abuse). Fortunately, through the Inclusion Across the Lifespan project, the guardians and I had built a trusting relationship, and they did not request any transcripts. In three cases, however, the parents were present for the interviews. As I stated previously, Stephanie and Kurtis' parents attended the interviews to help their children to understand the questions and me to understand the language that the children were using. In addition, Nicole requested that her mom stay for her interview. To ensure understanding, I told the participants with disabilities that their guardians might hear their comments, and I believe that each participant understood this—even the youngest participant, Stephanie. When I asked Stephanie whether anybody in her class bothered her, she hesitated and looked at her mom. At this point I said, "You don't have to talk about it if you don't want to," and she changed the topic to something that she did want to discuss. This allowed Stephanie to lead the interview and decide what she did and did not want to discuss.

Respecting the "Voice" of the Participants

Another difficulty that qualitative researchers might encounter occurs during the writing process itself. I relied on quotations to support my findings and "make a case" for my interpretations. Some individuals with developmental disabilities, however, have unique speech patterns that could be recognized if direct quotations are included in the research, and other speech patterns might appear different or absurd to readers and could result in disrespectful representation of the individuals. Therefore, I omitted from the case studies any speech patterns that I thought might identify or disrespect the participants in this study. I maintained the accuracy of meaning, but at times I changed the wording to protect the participants.

Storage of Data

According to the University of Alberta Research and Scholarship Integrity Policy 96.2.6 (2007), I will store all of the data from this project in a filing cabinet in a locked research office at the university for the mandatory five-year minimum. I made copies of the audio files available to a transcriptionist, who signed a confidentiality agreement. All computer files were kept on the computer in the research office and on the research team's secure laptop. I also backed up all of the data on compact discs, which are also secured in the research office. I have not disseminated electronically any of the information regarding the research participants and their interviews, except to individuals on the research teams at the University of Alberta and University of Prince Edward Island.

CHAPTER 4: RESULTS

Introduction

As defined in this project, a case consisted of the individual with a disability and his/her parents/guardians and, where applicable, teachers/employers. The focus of each case was the social experiences of the individuals with disabilities. In addition to analyzing the archived data from the Inclusion Across the Lifespan project, I conducted follow-up interviews with the key informants for each case study. For example, as stated previously, because the child chosen from the 3–6-year-old age group (i.e., Stephanie) was too young to provide in-depth information about her social relationships, her parent became the key informant. For all of the other case studies the key informants were the individuals with the disabilities. Although the parents/guardians and teachers/employers were not the key informants for most of the case studies, I have included their information when it provides further insight into the target participants' social experiences.

To ensure anonymity and confidentiality, I have changed the names of all participants. All grammatical errors in the quotations are a result of the verbatim transcription of the interview data to preserve the "voice" and meaning of the statements. To avoid unnecessary repetition, the case studies do not contain in-depth descriptions of the target participants, which can be found in Chapter 3. Instead, I describe and review the context of each interview to allow the reader to better understand the circumstances of and interactions within each setting. Following the depiction of each setting, I introduce the broad themes that emerged from the participant interviews. I did not necessarily decide upon these themes prior to the interviews; they often appeared as repetitive topics in the interviews and later emerged as themes as I coded the data. Under each broad theme or category I present subthemes and use quotations to illustrate the meaning of each. Table 3 provides a summary of each theme and subtheme as well as the particular participants that addressed those topics in their interviews. I then conclude each case with a final summary of the participant's social experiences. This portion of the dissertation is strictly descriptive in nature, and I will present an interpretation and comparison across cases in the following discussion chapter.

Table 3

Summary of Themes by Perspective

Themes/subthemes	Acknowledgment of theme																	
	Participant						Parent/guardian						Teacher/employer					
	S	K	N	E	B	L	S	K	N	E	B	L	S	K	N	E	B	L
Definition of inclusion	--	X	X	X	X	X	X	X	X	X	--	X	--	--	--	--	--	--
Definition of friendship	--	X	X	X	X	X	X	--	--	--	--	--	--	--	--	--	--	--
• Definition of "best friend"	--	X	X	X	X	X	X	--	--	--	--	--	--	--	--	--	--	--
• Importance of friendships	--	X	X	--	--	--	X	--	--	--	--	--	--	--	--	--	--	--
Types of friends	--	--	X	X	X	X	X	X	--	X	--	--	--	--	--	--	--	--
• Friends with disabilities	--	--	X	X	X	X	X	X	X	--	--	--	--	--	--	--	--	--
• Friends without disabilities	--	--	X	--	X	--	X	X	--	--	--	--	--	--	--	--	--	--
Activities with friends	--	X	X	X	X	X	X	X	--	--	--	--	--	--	--	--	--	--
Assistance making friends	--	X	X	X	X	X	X	--	--	--	--	--	--	--	--	--	--	--
Strategies to assist friendship formation	--	X	X	X	X	X	X	--	--	--	--	--	--	--	--	--	--	--
Support received from friends	X	X	X	X	X	X	X	X	X	X	--	--	--	--	--	--	--	--
Support given to friends	X	--	--	X	X	X	X	--	X	X	--	--	--	--	--	--	--	--
Relationships with family	--	--	X	X	X	X	X	X	X	X	X	X	--	--	--	--	--	--
• Impact on parents	--	--	--	--	--	--	X	X	X	X	X	--	--	--	--	--	--	--
• Impact on sibling	--	--	--	--	--	--	--	X	--	X	--	X	--	--	--	--	--	--
• Support received from parents	--	--	X	X	X	--	X	X	--	--	--	--	--	--	--	--	--	--
• Support received from sibling	--	--	X	X	X	X	--	X	--	--	--	X	--	--	--	--	--	--
• Support given to sibling	--	X	--	X	X	--	--	X	--	--	--	--	--	--	--	--	--	--
• Extended family support	--	--	--	X	--	--	X	X	X	X	--	--	--	--	--	--	--	--
Other relationships	--	--	--	X	X	X	X	X	X	--	--	--	--	X	X	--	--	--
Benefits of inclusion to participant	--	--	--	--	X	--	X	X	--	X	--	X	--	--	--	X	--	--
Benefits of inclusion to others	--	--	--	--	--	--	X	X	--	--	--	--	--	X	--	X	--	--
Social challenges	--	--	X	X	X	X	X	X	X	X	X	X	--	X	X	--	--	--

S – Stephanie (6 years old)
K – Kurtis (12 years old)
N – Nicole (15 years old)
E – Erica (28 Years old)
B – Bonnie (42 years old)
L – Lyle (63 years old)

Case Study 1: Stephanie (6 years old)

The Interview Context

Stephanie and her mom, Nancy, were both interviewed twice during the Inclusion Across the Lifespan project. During the interviews with Stephanie, Nancy requested that attention not be drawn to her daughter's disability. I did not ask any disability-specific questions and was cautious in discussing inclusion with Stephanie. She had not yet been informed that she has a disability, and her parents stressed that it is important to them that Stephanie see herself as a "normal" child.

Both interviews with Stephanie took place sitting on the floor, once in her playroom and once in her living room, so that Stephanie could move around and play while talking to me. On several occasions we had to take small breaks before she would answer the next question. We would play with her toys for a few minutes and then proceed with the interview. Nancy was present at both of Stephanie's interviews to keep her daughter focussed and help me to understand Stephanie's verbal language because she sometimes had difficulty forming certain words or sounds.

The interviews with Nancy took place in a private setting where Stephanie could not hear her mother's responses. For one interview, Nancy came to the research office to ensure privacy. During the second interview we sat in her kitchen while Stephanie played in the living room. If Stephanie entered the kitchen, we would take a break from the interview until she returned to play in the living room. The follow-up interview for this dissertation again took place in Nancy's home, but on this occasion Stephanie was at school.

Nancy was very open during her interviews and talked at great length about Stephanie's social experiences. She thought that this project is an important information source for the community and was interested in what other parents and teachers had to say about social inclusion because she thought that others' experiences would benefit Stephanie. She was also interested to hear my personal opinions about topics such as the benefits of inclusion. Following the interview we had an informal conversation about my experiences in the settings in which I have worked.

Definition of Inclusion

Nancy defined *inclusion* as Stephanie's being treated just like any other child. She stressed the importance of this throughout her interview.

> I guess that my daughter be treated like every other child—have the opportunity to do things that every other child does and be able to participate in the same way that they do.

In addition, she saw inclusion as an opportunity to get to know people. She expected that Stephanie would meet people inside as well as outside of her classroom. She described inclusion as a whole-school rather than just a classroom concept and feels that it is the responsibility of all staff in the school rather than just the educators. In her opinion this opportunity to meet others does not always occur naturally, sometimes, adults in the environment need to provide opportunities.

> I think it can happen. I think you've got to keep an eye on it constantly and look for ways to facilitate and make opportunities and help your kids learn the skills.

It became clear during this discussion that Nancy not only wanted equal treatment for Stephanie, but she also expected equal opportunity for her daughter, and this has sometimes meant extra effort from the adults in her environment.

When I asked whether there had been a critical incident that helped to form her definition of inclusion, Nancy described an incident that occurred when Stephanie was about to enter preschool. Her community preschool had told Nancy that it was unable to meet Stephanie's needs and therefore refused her enrolment. The school had many excuses for this action but, after a long fight, the school allowed her to enrol. Stephanie's parents, however, chose not to enrol her in a setting in which there had been so much resistance. This incident surprised Nancy because she did not expect to face a struggle at such an early stage. This made her very determined and gave her a "reality check" about inclusion.

> So I started to get my skills tuned up about what things we might have to do for down the road. It came pretty early when you really didn't expect it to be that kind of resistance.

Nancy also described a presentation that she attended that helped to shape her view of inclusion.

> I think another critical thing was, I attended a conference and a fellow spoke, and he talked about being in special schools and that when you get out of special school there's no special McDonald's, there's no special movie theatres, and how can you deal with a regular restaurant or a theatre when you've been "special" your whole life? You need to be in regular so you can deal with regular because those things aren't fair later on.

This is a topic to which Nancy kept returning in her interviews, and it seemed to be the key to her definition of inclusion.

Definition of Friendship

During our discussions about friendships, Nancy described how her definition of friendship would differ from Stephanie's. Stephanie's definition of a friend is simplistic; A friend is someone with whom she plays or someone who likes her. To Stephanie, a best friend is the person with whom she spends the most time. Nancy, on the other hand, defined a friend as:

> Someone who accepts you the way you are, and someone who supports you and likes to be with you and interact with you. And you have some common interests or things.

Also, according to Nancy, a best friend is someone who is "always there."

> For me, personally, I guess it's someone that I know is always there and just always a part of my life, and you can always rely on. And just kind of someone through thick and thin.

Best friends are different from regular friends in that the bond is stronger and they can be relied on for anything. Nancy was not sure, based on this definition, whether Stephanie has a best friend or not.

Nancy thought that Stephanie's friends should accept her differences and was concerned that Stephanie needs more shared interests with her friends so that they will have increased opportunities to play together. She also defined a friend as "someone you feel comfortable with and can communicate with." She was concerned about Stephanie's ability to communicate with her friends, which is an important part of friendship development. Friendships are very important to Nancy.

> That is what life is about. It's about relationships and friendships, and, I mean, when it comes down to it, that's what it all ends up being, right?

Nancy believes that social relationships are the foundation for all other aspects of life and essential to community living. Friendships offer opportunities to network in the community and gain support.

Types of Friends

Stephanie's teacher described Stephanie as being well accepted in the classroom setting. She stated that all of the students in her class were friends and that Stephanie has been well included.

> Friends are a funny thing. You have a few that sort of pair off, but generally they're all just—we're all friends, and there isn't a lot of "I want to be with this friend," "I don't want to be with that person." So we tend to be very inclusive of everybody. And then there's always boy and girl stuff and things like that. So it hasn't been a problem. . . . I've never seen a child say, "Why isn't [she] talking more?" There's never been a question, so she's just part of the group.

Nancy described Stephanie as having friends both in and outside of school. She feels that it is very important for her daughter to have interactions outside of the school setting. Stephanie's parents have made a great effort to schedule social events for her outside of the school setting. All activities in which she takes part with her friends have been initiated by either her parents or her educators in school. Stephanie rarely independently plans activities or events with her friends.

Most of her Stephanie's friends do not have disabilities, but one friend does.

> You know [the other little girl has] a little challenge with her walking and what not, and they've just—I guess by virtue of the fact that they're usually a couple of the last ones out for recess, they are sort of together. So I mean, circumstance brought them together, but they obviously have been able to make a friendship out of it, too.

Stephanie has been able to form a friendship with the other child in her class who also has a disability because they share similarities and often find themselves in proximity to each other. This is consistent with Nancy's report of how Stephanie would define friendship.

Assistance With Making Friends

Stephanie has received support in forming friendships from several sources. First, her family has made a strong effort to help her to fit in.

> Just kind of hide [her disability] and don't make a big deal. So I think when kids don't really see each others' differences, they're just a lot more accepting, and my friends and the moms that I hang around with, they're really good about inviting her to parties, and she goes to birthday parties all the time. She had nine kids at her birthday party, and she's got a lot of friends, and I think just making the effort to be part of your community—your community stuff really helps.

Nancy attempts to provide opportunities for social interactions whenever possible. She reported that, over the summer, she attempts to schedule at least one structured play date per week.

Furthermore, Stephanie's friends' parents have helped her to form friendships.

> And I guess . . . her friends' moms—parents—as well. I have friends who, when she was just kind of going on her first play dates without me, were very good about saying, "Don't worry, I'll look after her. I'll phone you if there's a problem." Or "Just drop her off for the birthday party; you don't need to stay." And so they sort of stepped up just to make me feel comfortable and have an extra eye for her.

This seems to provide Nancy with some relief and assure her that Stephanie will receive assistance from additional sources.

The staff at Stephanie's school have also helped to create social opportunities. Nancy described the vital role that Stephanie's educational assistant has played in setting up opportunities.

> Because at recess they're running around really quickly and screaming and yelling, it's harder for her to engage a little bit because she's a little slower getting out. The play is already started. She's a little more timid to join in. So certainly the aide has been trying and continues to sort of facilitate getting her with some other kids and then will try and back out. But either give her some language or sort of take her over; you know, get a discussion going or something.

Without this assistance to overcome the communication challenges that she faces, Stephanie's social interactions would be limited. Nancy also contended that the other staff in the school environment should play a role in assisting with Stephanie's social interactions. She named the principal of Stephanie's school as the leader of this initiative.

> It should be sort of a common school goal, and I'd have to say, I think our school in particular—I have nothing to compare it to, but, I guess I should only say in regards to that then—they sort of have a focus on that community building. For instance, one of their school mottos is "You can't say you can't play." So when kids are playing at recess, everybody's welcome.

Moreover, Nancy also considered community support essential in providing opportunities for social interaction.

> She knew everybody, or everybody knew her, so it's sort of just community awareness, which is good because I think all those people that know her will just, hopefully, as you would for someone else you knew, keep a little eye out, whatever—saw her in need or something. . . . And going back to all the other stuff we talked about—exposing your kids and letting them know and be known, right? And having a community network is really important.

By exposing Stephanie to community activities, Nancy hopes to gain additional support from community members because this exposure will create further opportunities for Stephanie for social interactions and social supports.

Strategies to Assist Friendship Formation

The strategy that Nancy identified as most important in Stephanie's friendship formation is to ensure that she, as her mother, helps her to seize any opportunity for social interactions, including involving Stephanie in community activities such as t-ball or soccer. Nancy stated several times in her interview that children with disabilities need opportunities to form friendships.

> I think opportunity has to be with kids for other people to be able to be friends with them. You have to have spend time together to figure out if you have things in common and be able to have the opportunity to dialogue or communicate or whatever it is—play together, depending on what stage you're at—to know if you like somebody.

According to Nancy, props sometimes help to facilitate social interaction and create such opportunities.

> Props of whatever sort of thing help. It's a coffee if you're an adult, or the swing sets, the play sets, the swimming pool. It always helps to get things going.

Sometimes Nancy places Stephanie in situations that are beyond her "comfort zone" to increase her ability to deal with challenging environments and further create opportunities for social interactions once she builds up this capacity.

> Pushing her a little bit past her comfort zone—a little bit of a louder place, a little bit of busier place, a little bit of a place with more kids—just pushing the envelope because . . . it's easy to go just to a nice little quiet spot that she likes, right? But it's not as fun to go out where it's loud and noisy, and she gets uncomfortable sometimes. But she's never going to be comfortable in a gym class with kids screaming if she's not exposed to that. So, yes, just pushing her boundaries.

Within these opportunities, Nancy suggested that Stephanie needs to learn social skills to appropriately interact with her peers.

> You have to learn how to put yourself out there a little bit, maybe take a little risk; talk to people. And you have to learn how to share kind of at a basic level, right? Take turns. [Laughs] Show interest in the other person and expect the same back, so it's not just one-sided; gain consensus, . . . so little kids deciding what they're going to play. Or in adulthood, "are we going to a movie or are we going shopping?" . . . We have to be able to agree on things and learn how to do that.

Nancy recommended that children with disabilities be prepared for opportunities and have the appropriate social knowledge to succeed. According to Nancy, children need to be prepared for the environment to ensure that their social interactions are successful. This includes the willingness to participate in friendships and knowledge of the benefits of friendships.

> Willingness and a desire to want to have friends and be a friend has to be there too, and understanding that it's a great thing to have and be a friend and to want to do that.

This is a theme that recurred throughout the interview and will be discussed in further detail in the social challenges discussion.

Support From Friends

Both Stephanie and her mom were able to name ways in which Stephanie's friends support her. Stephanie stated that her friends assist her with physical tasks such as using the restroom and simply playing with her.

> Interviewer: How do they help you? To go potty?
>
> Stephanie: [Stephanie nods.]
>
> Interviewer: Do they help you do anything else?
>
> Stephanie: Just play

She considered spending time with her friends as assistance.

Nancy discussed additional support from Stephanie's friends. For instance, they watch out for her and offer physical support when she needs it.

> I think they kind of keep a little eye out if she needs a hand with something. It just sort of seems they do it sort of naturally without really thinking about it. When they were walking to the office to do the prayer, one of the little girls was just holding her hand, so it's just kind of "I'll help you get there" and held her hand on the way back. And just mak[ing] sure she's kind of going in the right direction.

In class activities, if Stephanie struggles, her friends assist her so that her aide does not have to interfere with the natural social interactions in the setting.

> So they support her with tasks and activities. They support her with just help to make the game go better.

Stephanie's friends also offer her emotional support at times.

> [If she] is crying or upset about something, they'll, at recess, go and tell someone, or have come and told me if it's been a play date or something like that, so they're just looking out for her to make sure that she's okay.

Even at a young age, Stephanie's friends have been able to meet both her physical and her emotional needs, whether it is by offering support themselves or by getting assistance from someone else.

Stephanie's Support of Her Friends

Like the support that she receives from her friends, Stephanie saw just playing with her friends as a way in which she helps them. Similarly, Nancy stated that Stephanie offers assistance to her friends in the same way that they support her: She watches out for them and assists them if they need it.

> She's noticing that one little boy at school at recess. The other kids were—I don't know; I can't remember what she said—[inaudible] or something. And she noticed it, right? And . . . the boys play rough, so I don't know if they were just playing or—but she singled out one that she didn't think was enjoying it, and she told me about it. I said, "Well, did you go and tell the supervisor?" And she said she did. So . . . at least I was planting in her brain that she needs to look out for her friends. They need to look out for her, look out for each other, and "You go tell someone if it doesn't look like someone is having fun."

Nancy saw the support between friends as mutual: Sometimes Stephanie needs assistance, and at other times she is able to offer assistance. At times Stephanie's friend who has a disability requires physical support, and Stephanie is able to provide it.

> She is helping somebody get dressed at school or helping with their work. I don't know exactly what that means. [Laughs] But that's what the assistant was telling.

Stephanie is also able to offer her friends emotional support if they are upset.

> I think she's very sensitive to other people's emotions. So if someone is upset, I think she really empathizes with him/her and will try to comfort them with a hug or a gentle touch or something like that, or pay attention to them.

Stephanie is not always the receiver of help, but she also has the opportunity and ability to help her peers.

Relationships With Family

Stephanie is the only child in her family; therefore no discussion of siblings is included in this case study. Nancy did, however, note that her social inclusion has impacted her and her husband. Nancy reported that, overall, she has been positively impacted by her experience with her daughter because Stephanie has made her more open-minded.

> I guess just being more open minded myself, just being more cognizant of challenges that people face or how we can make the world more accommodating. As we're trying to open up things for her, we kind of realize that maybe inadvertently in the past we took things for granted. It just made me more cognizant of equity and equality in terms of people's different lifestyles and acceptance of people. I think, hopefully, I was pretty good at that, but you're much more tuned into it.

Stephanie's inclusion has been a learning experience for Nancy; as she began to learn more about her daughter, she began to learn more about equity for all individuals.

A negative impact of Stephanie's inclusion that Nancy identified is that advocating is at times very time consuming.

> I'd say, in a way [there is a negative impact], because the world is not as inclusive as you'd like it to be. I say I have a full-time job now advocating, and it's a lot of work, and, unfortunately, lots of things take more effort than someone who can just sign their kid up for an activity or sign them up for a school and not think twice about it. You've got to go through lots more rigmarole and a lot more hoops. You find out about programs and funding and this and that. Unfortunately, there's lots more time that you would rather spend with your child than talking to people on the phone.

Although Nancy believes that inclusion is "worth the effort," she noted, on several occasions, that a great deal of effort is involved and stated that this has increased the stress in her life.

In addition to Stephanie's parents, Nancy reported that their extended family also supports Stephanie. It is interesting that she did not identify any disability-specific supports but stated that the best support from their extended family is their unconditional acceptance of Stephanie.

> I think the best way [that our family supports Stephanie] is that she is just one of the family—she's just one of the family. She's a second cousin, so a cousin, and they just let treat her no different. They play with her and include her and stuff like that. They're very supportive emotionally, I guess, if that's needed, or just by the fact they just make it all normal.

Despite any challenges that Stephanie faces in other settings, she is always well accepted within her family environment. Family relationships are very important to Stephanie. Nancy described her daughter's relationships with her family members as "more than friendships." She can identify all of her relatives and seems to have a close relationship with all of them.

> She has a real sense of family and, I think, you know, friends can change, but family doesn't. Her cousin [Christy] is her favourite cousin. . . . She just has a real amazing sense of family. And she knows relationships, and she knows this person is her aunt, and this is her cousins' parent and my brother or sister-in-law or whatever. At an early age she started to really understand the connections and the different roles people play and how family is: You do this with your family, and family is really important. She'll talk about our family, and her grandparents, it's a whole other relationship, too. She loves her grandparents, all of them. Has different games she plays with each one. They all have a special thing that they do. And . . . she's got her favourite aunt, [and] they do their special things. And yes, family is like a whole different kind of category.

Other Relationships

In addition to Stephanie's relationships with her family, Nancy identified several other relationships in various settings. Stephanie is aware of many different categories of relationships outside of friends and family. One that Nancy talked about in some detail is Stephanie's relationship with her friends' parents. In particular, Nancy mentioned one mother with whom Stephanie has a "real connection" and who always makes an effort to spend time with Stephanie whenever they see each other.

Stephanie is also able to identify the differences between her own and her mother and father's and grandparents' friends. Her mother said that Stephanie does not identify all of these people as her friends but is able to understand that they are somebody else's friends. Nancy spends a great deal of time discussing friendships with Stephanie, and this ability to identify others' friends illustrates this effort.

Stephanie is also able to identify strangers, which she was taught to ensure her safety. According to Nancy, she can identify "who makes a stranger, when it is okay and not okay to talk to someone." Moreover, Stephanie knows that she can interact with individuals such as her dentist, doctor, teacher, swimming instructor, and babysitter even though they are not her close friends.

Benefits of Social Inclusion for Stephanie

Nancy discussed the importance of, not only friendship, but also social inclusion in general. Without social inclusion Stephanie would not be able to "be part of [society] and contribute to it and benefit from it and take advantage of everything that life's got to offer." Nancy believes that "an individual has to be with it in order to be part of it."

Social inclusion provides an opportunity to learn from peers and learn appropriate behaviour for later life.

> I think she learns from her peers. She sees what they do and learns how to behave or misbehave—just how to react. She learns that the world is not all about her. I think when there's too much adult interaction kids get . . . I mean, as much as the whole early-intervention philosophy is follow-the-lead, child-centred, I think kids can get a little bit too self-centred. Kids being with other kids and peers kind of ground them into that they have to learn how to negotiate and communicate and not always have their way.

Because of her social inclusion, Stephanie has the opportunity to learn negotiating skills that may assist her in finding solutions to difficulties in the future.

Benefits of Social Inclusion for Others

Not only Stephanie, but also those around her have benefited from her social inclusion. Nancy suggested that Stephanie's peers have an opportunity to learn about diversity and difference.

> I think they learn about different styles that kids have. She will probably be more quiet so they learn how to be—or maybe more gentle and stuff so that they learn that kids come in different packages sizewise, their communication skills, and things like that. So they learn about diversity and just dealing with different types of personalities.

Stephanie's peers have learned different interaction patterns and social skills because of Stephanie's inclusion. They have also learned about acceptance at a young age. In addition, Nancy feels that Stephanie's peers benefit from her personality because "she's got a great sense of humour and stuff."

Social Challenges

Though Nancy views Stephanie as being fully included in her community, she and her family have also faced challenges. Nancy described a recent struggle with disability awareness education. One of Stephanie's peers had recently learned of

Stephanie's disability, and Nancy was unsure whether other children were beginning to notice. According to Nancy, Stephanie is not yet aware that she has this particular disability.

> Has she noticed a difference? Sometimes she tends to be less confident; I don't know that she notices that she's different. She'll say, "I'm not a good reader," but I don't know if that's necessarily comparing herself or she's just frustrated because she can't get a word. I don't think she knows. Our philosophy is, "You're just another six-year-old kid, and just be another six-year-old kid"

Nancy and her husband were debating whether and when to tell Stephanie's peers about her disability and when to tell Stephanie the details of her disability. Nancy did not want Stephanie to be "blind-sided" and learn about her disabilities from someone else, but, on the other hand, Nancy did not want to place a label on Stephanie at such a young age. "The fact that she has a particular program is no different than lots of other kids." Therefore, Nancy did not want to limit Stephanie by using a particular label.

Related to Nancy's discussion of Stephanie's inclusion being time consuming, she reported that having to make an effort to provide extra support can also be a challenge for both Stephanie and herself.

> [A parent] definitely needs to do extra things. You can't just take for granted that these things will happen. You need to facilitate it, provide opportunity, and it's harder work, I think, than just a kid who just goes out to play. . .There's a few more barriers that you have to be conscious of; you have to look for ways to overcome and get through.

Stephanie, at times, faces challenges that other children might not, and Nancy viewed these challenges as an added responsibility to her parenting duties and extra pressure with which Stephanie has to cope.

In the school environment Stephanie's teacher described how Stephanie's difficulties with verbal communication have provided a social challenge for her in the classroom.

> I would say that the biggest drawback would be her language development, so that if she's playing with a group of children, they may feel that she's not taking part in what they're talking about, and so I think, if anything, that might affect her play with them.

Stephanie's teacher called for extra effort to assist Stephanie with her communication to avoid losing opportunities for social interaction. Some of the children in the class have had a tendency to "baby" her and want to take care of her because of her small stature. Her teacher saw this as a challenge because it can also reduce opportunities for mutual peer social interactions.

Nancy also identified this difficulty with communication and reported an incident in which, when a classmate had bullied Stephanie, she was not able to describe the situation effectively. Stephanie did not want to go back to school for a period of time, and Nancy did not know about the bullying incident until another parent informed her. The school also inadvertently exacerbated the problem by not reporting the incident to Nancy.

> I would have liked to have been told about it immediately so that we didn't go for a week with her waking up and saying, "I don't want to go to school. I don't want to go to school," because she was obviously afraid of something. [And they never told you anything?] Well, I brought it up when this mom had talked to me. I guess they felt that they had dealt with it, but obviously they didn't. And I think when you have kids who can't communicate as well, you need to inform family so that they can look for signs that something is not right and yet without being leading but being able to help the child then be able to identify what's going on.

Nancy discussed the additional frustration that she feels because sometimes Stephanie rejects the interaction when her peers approach her to play. Nancy was unsure whether this is related to Stephanie's disability or whether she prefers to play alone because she has been brought up as an only child. This challenge surprised Nancy because she was prepared to have to cope with others rejecting Stephanie rather than Stephanie rejecting interactions with others.

> I think you need to keep your eyes open too that it's not always someone else, but it may be your child that doesn't have the skills or understanding that friends are important. You need to make an effort just as much as somebody else; . . . see the benefit of playing with peers versus adults.

Nancy stressed the need for Stephanie to learn the importance of peer relationships and interacting with peers and reported that this was a goal on Stephanie's IPP in kindergarten.

> I think kids with disabilities can get caught up in the adult world. There's lots of them around helping them, teaching them, giving them therapy; and we're all understanding and accommodating so kids can get very comfortable. . . . This is the world I want to be in, . . . not this more challenging kid world where if I don't say it right that first time, they walk away or whatever. . . . So I think we have to make sure we're not throwing kids into this false world, which is not really the peer world.

A final challenge that Nancy reported was that Stephanie was not yet fully toilet trained. Nancy feared that, because this is not an age-appropriate trait, it could have social consequences.

> Other kids are starting to notice the pull-up or something like that, and there's been some comments made lately and things like that, and I start to worry about things like that.

Stephanie's mom feared that this challenge could result in Stephanie being rejected or bullied by her peers.

Summary

According to the interviews with Stephanie, her mother, and her teacher, it seems that Stephanie does well socially. She is able to take part in mutual relationships and has friends both in school and in her community. Additionally, she is able to identify different categories of relationships and distinguish her friends from others' friends. Despite Nancy's concern that Stephanie may not yet fully understand the concept of friendship, it is clear that Stephanie has learned to take part in reciprocal interactions and knows the difference between friends and others. Nancy considered teaching Stephanie the "safe" people to talk to (e.g., her doctor, but not strangers) an important factor in her personal safety.

Stephanie's social success did not come easy. Nancy discussed the many hours that she had spent advocating for Stephanie's inclusion. Even at this young age Stephanie has encountered roadblocks to her community inclusion that need to be overcome for her to have the opportunity to interact with her peers. It is important to Nancy that Stephanie be treated as "normally" as possible, but sometimes this requires a great deal of time and energy. She has to take care in setting up opportunities for Stephanie to ensure not only equal treatment, but also equal opportunity for social interaction. Stephanie was not yet initiating social interactions independently, and Nancy and other adults had to facilitate social interaction by setting up structured activities for her with her peers.

However, not only does the setting need to be prepared for Stephanie, but she also has to be prepared for the setting. This preparation includes teaching her age-appropriate social skills, ensuring that she understands the value of friendship, and pushing her beyond her comfort zone to build her capacity to deal with more challenging environments. With this opportunity and preparation, it is clear that Stephanie is learning about friendship and the skills that she needs to take part in meaningful friendships. Many of the individuals whom Stephanie identified as friends are those in closest proximity to her, but with more opportunities, this “circle of friends” is growing larger, and Stephanie’s network of social relationships is increasing.

Case Study 2: Kurtis (12 years old)

Interview Context

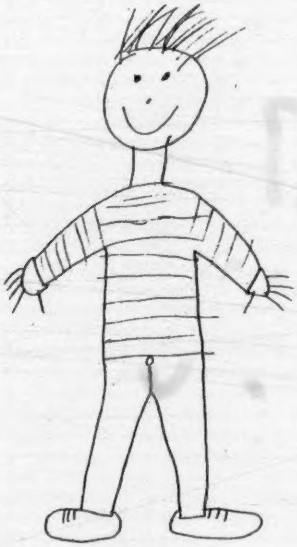
Prior to this dissertation research, Kurtis had been interviewed at his home twice for the Inclusion Across the Lifespan project. Both of Kurtis’ parents attended these interviews to help him to focus and form answers when he became confused. They knew the prompts to use to help Kurtis most effectively answer the questions. Kurtis parents and teachers/teaching assistants were also interviewed as supplementary informants for the Inclusion Across the Lifespan project.

The arts-based interview for this dissertation took place in a private office at Kurtis’ school. Because of his autism and the challenges that he faces on a daily basis, Kurtis is often fatigued at the end of the school day, and his mom thought that it would be best for him to be interviewed during school hours. She gave her permission for Kurtis to miss part of his afternoon class for the interview.

At the beginning of the interview Kurtis was very focussed on a school project that he was supposed to be working on during that time period. I assured him that the interview would not take too long and that he would be given time to finish his project later. However, he continued to worry about the length of the interview, and I made a deal with him that if he would allow me to interview him, the interview would not extend past the end of the first period. Fortunately, we were able to discuss most of the questions that I wanted to ask in this time period.

During the interview I asked Kurtis to draw some pictures to help me to explore his social interactions. He became anxious and replied that he did not remember enough to draw a picture. To ease his self-consciousness, I asked him first to draw a picture of himself (Figure 5). After Kurtis completed his picture, I praised his efforts, which helped him to gain confidence, and he became more willing to complete additional drawings.

Figure 5. Kurtis' self-portrait.



Kurtis' educational assistant cautioned that the interview might be more difficult that particular day because Kurtis was having an "off" day. In the morning, Kurtis had behaved in a manner that indicated to his teaching assistant that he was tired and easily frustrated. Throughout the interview Kurtis appeared more tired than usual and needed a great deal of prompting to continue the discussion on his social interactions. On a couple of occasions we took short breaks to allow him to discuss any frustration that he was feeling and to focus on his school project for a few minutes. This seemed to satisfy Kurtis and assure him that I understood his emotions, and following each break, he would relax.

Definition of Inclusion

On several occasions during the interview I asked Kurtis, "What does inclusion mean? What does it mean to be included?" but he did not know. Even with his parents' prompting, Kurtis did not demonstrate any understanding of the concept. Though his definition of inclusion did not emerge as a theme in his case study, it was interesting to note that Kurtis was not able to articulate what inclusion means even though he had been included for most of his childhood. It seems that, although he was placed in inclusive settings, no one had directly broached this topic with him; rather, it was a natural component of his community living.

Kurtis' mother, Lena, defined inclusion as Kurtis' involvement in activities with his peers. She stated not only that it is important that he be in the same environment with his peers, but also that accommodations are needed to ensure successful inclusion.

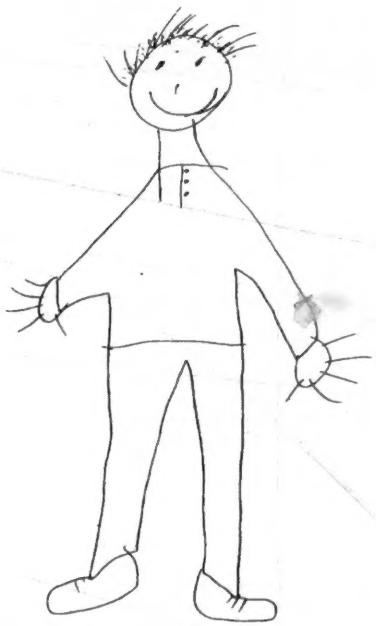
> I guess just making accommodations so that [Kurtis] can manage on his own somewhat at school, and just, . . . I think it's important that he's with the other kids a lot as well. He does have his time in the special-ed room, but it's never just one-on-one; usually it's with a group. So I think that's important. I think he doesn't seem to be segregated at all; he just carried on with the rest of the kids. He's with the same bunch that he's always been with, so I think that helps.

Lena's definition contained two aspects: (a) the presence of other children and (b) supports to assist with his functioning within the social environment. She felt that, overall, Kurtis has been very much included in his school and community.

Definition of Friendship

According to Kurtis, being a good friend means "being nice to your friends" and "playing soccer with them." In his art, Kurtis drew a picture of his friend Ivan (Figure 6) and told me that Ivan is his best friend; he further defined his relationship with Ivan as "a pal." It is interesting to note that Kurtis' artistic representation of Ivan is very similar to his self-portrait but provided him with a focal point to describe his relationship with Ivan. They are friends because they are "in the same gang together." It became apparent from Kurtis' descriptions that he based his definition of friendship on other individuals' proximity to him rather than on intimate interactions. When I asked why he thought friends are important, he stated that he needs them for "partners in groups." He recognized his friends as people who can provide him with assistance when he needs it, such as in working on school projects in groups. In addition, he described his best friend as someone with whom he spends time playing and having fun.

Figure 6. Kurtis' representation of his "best friend."



> Interviewer: Why is [Ivan] your best friend?
>
> Kurtis: 'Cause he's the greatest.
>
> Interviewer: Why is he the greatest?
>
> Kurtis: Well, because we have such a great time.

When I asked Lena about Kurtis' definition of friendship. she was concerned that he might not fully understand the importance of friendship because of his disability.

> See, I don't really think he really knows what friends do. He knows that they help him at school, but he doesn't have the same sort of relationships with a friend that other kids do I think maybe . . . he doesn't seem to need that like the other kids.

Kurtis had a more simplistic definition of friendship than some of his peers might have had, and his mom was aware of this difference. Kurtis did, however, acknowledge that his peers could provide him with help, so he was able to identify at least one function of friendships.

Types of Friends

Kurtis seems to prefer to spend time with male peers, which is thought to be typical behaviour for many Grade 7 boys.

> Interviewer: And is [the girl who sits beside you in class] your friend? Do you spend time with [her]?
>
> Kurtis: No, just me and the boys.

According to Lena, however, the females in Kurtis' class did provide him with social support at times

> He talks about the girls that help him at school and whatnot more—more so than the boys.

Neither Kurtis nor Lena discussed whether Kurtis' friends have disabilities. However, Lena reported that Kurtis' best friend, Ivan, was also a student who attended special-education classes. Kurtis may have identified Ivan as his best friend because he spent the most time with him in school, in both the regular and the special-education classroom.

Activities With Friends

Lena reported that Kurtis spends a great deal of time with his friends in school because of the structured activities in that setting, but that he spends very little time with his friends outside of school.

> Outside of family friends and things like that, he'll very seldom ask to have a friend over or go somewhere else. He likes home, but he likes having kids over for his birthday, and he likes to know if we can have the kids over for a swim or something. But he's not like the other kids where they ask lots [to have their friends come over].

According to Lena, Kurtis enjoys activities if they are scheduled for him, but he does not independently seek out these activities (e.g., asking whether his friends can come over to play). Similarly, Kurtis stated that he spends time playing with his friends at school, but that he sees his friends outside of school only "once in a while." He does not like to talk on the phone with his friends, and he stated that he does not go to his friend's house. On rare occasions his friends would visit him at his house. When I asked Kurtis to draw a picture of something that he liked to do in his spare time, it was interesting to note that he drew himself taking part in the activity (i.e., swimming; Figure 7) by himself. I further queried his picture, and he stated that sometimes he would swim with his family, but he did not mention participating in this activity with his friends.

Interviewer: Where do you go swimming?

Kurtis: Well, I have a pool in my yard.

Interviewer: Oh, right. And who else goes swimming with you?

Kurtis: My sisters.

Despite the lack of interaction with his friends outside of school, however, Kurtis reported that he would like to spend time with his friends rather than be alone.

Interviewer: Do you like to be with your friends, or do you like to be by yourself?

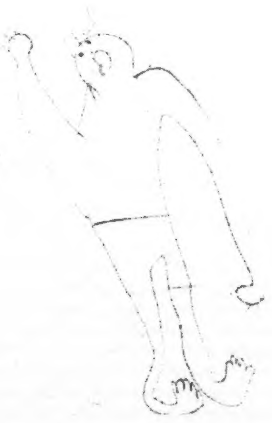
Kurtis: I like being with my friends.

Interviewer: With your friends. How do you feel when you are by yourself?

Kurtis: Well, feeling lonely.

This indicates that, even though Kurtis has a desire to be with his friends, he may not know how to initiate social activities and may have to rely on structured activities for social interactions.

Figure 7. Kurtis' representation of his favourite leisure activity (swimming).



Assistance With Making Friends

When I asked Kurtis, "Is there anyone that helps you to make friends?" he did not identify anyone who had helped him to form friendships. All of the friends whom Kurtis identified have been in his class since kindergarten; therefore the friendship formation occurred over a long period of time as a result of proximity. Kurtis could not remember how he became friends with his peers because it had occurred such a long time ago.

Interviewer: And how did you become friends with your friends?

Kurtis: Well—

Interviewer: How did you become friends with [Ivan]?

Kurtis: I can't think.

Interviewer: Did you ask him to be your friend?

Kurtis: I don't know. That was a long time ago.

Relationships With Family

Kurtis' parents, Lena and Neil, described Kurtis' relationships with his family in a positive light. They stated that Kurtis functions well within the family unit and that he "fits in." According to both Lena and Neil, the only negative impact that Kurtis' inclusion has had on them is that at times it takes longer to accomplish things.

> Lena: I suppose maybe it's more work, more time spent. . . . Everything takes him longer to do, so there would be more work to get him to read and more work to help him along.
>
> Neil: Because if you didn't, he would do nothing. He's one of these kids that they talk about [putting] on the shelf somewhere, and he would do nothing. . . . If that's all you wanted out of him, that's what you'd get.

They believe that it is important for them to have high expectations for Kurtis, and this sometimes requires that they put a great deal of effort into his inclusion.

Kurtis has two sisters, one older and one younger. He reported that he does not get along with his sisters.

Interviewer: Are your sisters your friends?

Kurtis: They're just my sisters.

Interviewer: Just your sisters. You don't call them your friends?

Kurtis: Nnn. [Negative]

Interviewer: Do you like spending time with your sisters?

Kurtis: [Sighs] No.

Interviewer: No? How come?

Kurtis: Because—'cause we're all three of us are so annoying.

Interviewer: Oh no! Who tells you that?

Kurtis: The most annoying one is my little sister.

He complained that his sister gets him into trouble, but his mom was quick to remind him that he does the same thing to his sister. Both of Kurtis' parents saw humour in his description of his relationship with his sisters. Lena stated that Kurtis gets along well with them.

> Lena: [He gets along with them] good, really good. [His older sister] will be thirteen tomorrow, and [his younger sister] is a little over seven, seven-and-a-half, so he's in the middle, so he gets it from both sides. [But his older sister] helps him a lot. She's really patient with him. [His younger sister] is good with him too, but she's—
>
> Neil: —a pain in the—[laughter]—which is good in a way. You've got to have that [in life too].
>
> Lena: She's a little more assertive, and she doesn't let [him] get away with things like [his older sister] does. [His older sister] is kind of an easygoing personality. . . . But now he gets along with her.

Lena and Neil talked about Kurtis' "normal" conflict with his sisters, but they were glad that his youngest sister does not always back down from him. They felt that her stubbornness gives him strength of character and will teach him how to deal with conflict in the future.

Lena also reported that having Kurtis as a brother has positively impacted his sisters. He has a different perspective from those of his sisters that they might not have been exposed to if not for their relationship with him.

> I think it's neat because he says things as they are. If somebody is going away, "Well, I'm really going to miss you," and he's meaning that, or "I thought you'd never come home." Everything is to the nth degree. So I think it's nice for them to see that part of it. I think there's no grey area with him, so it's either one way or the other way.

Lena also reported that the family has also "learned to be more patient" because of their interactions with him.

On the other hand, having Kurtis as a sibling does, at times, result in decreased opportunities for community interactions for his siblings. Sometimes the family is not able to attend community events because of Kurtis' special needs.

> We can't go somewhere due to his allergies or if we can't do some things because . . . he can't be part of it.

However, Lena felt that this lack of mobility does not greatly impact her daughters or seem to bother them.

Regardless of any conflict that Kurtis has with his sisters, when I asked him, "How do your sisters help you?" he reported receiving assistance from them when he needs it.

Interviewer: Do your sisters help you sometimes?

Kurtis: Yes.

Interviewer: What do they do to help you? Your big sister helps you, right?

Kurtis: With my last year's spelling.

Interviewer: And does your little sister help you with anything?

Lena: She was helping you with the reading and tying shoes.

On occasion, Kurtis struggles with his language-based school subjects and needs help with spelling and reading.

Kurtis was unable to report any way in which he assists his sisters, but Lena explained that he helps them with their chores. He agreed that every now and then he helps to complete his sisters' chores.

As well as his relationships with his immediate family, Lena described Kurtis' relationships with his extended family: "There's quite a few of us around," and they have family gatherings such as meals or birthdays that give Kurtis an opportunity to interact with his relatives. Even though for a period of time there might be no communication with their family members, Lena knew that they could still be depended on for support. She appreciated having family nearby if they need to call on somebody for help.

> My sisters are good. We don't see as much of [Neil's] family. . . . Actually, my family, we're not stuck to each other either. We all go for two or three weeks without talking to anyone, my one sister, but that's just the way it is. We don't have to be with each other the whole time, but yet I know that we can go and do something or I can phone her.

Other Relationships

Neil, Lena, and Kurtis' teachers and teaching assistant discussed Kurtis' relationships in the school environment and community as a whole. Lena stated that

Kurtis is well accepted in the community. Their family has a "good network of kids—friends—that have totally accepted him for what he is." Both Lena and Neil reported that Kurtis had never been ostracized within the community. Furthermore, they believe that his acceptance is a result of their living in a small community and the rural advantage that Kurtis has.

> Neil: And [they] haven't tried to ostracize him at all for his disability at all. Everybody's accepted him
>
> Lena: Yes, that's just [him]. That's it.
>
> Neil: It's just the way he is.
>
> Lena: Yes. That's just him.
>
> Neil: And it is because we are living in a smaller town. Whether he's going to get the best education in the world is another story, but I think all this interaction, the social interaction—
>
> Lena: Well, I think in some ways . . . lots of things he probably does get better.

Kurtis has not been defined by his disability in his community because "everybody knows him and he knows everybody." The community members had watched Kurtis grow up and have personal relationships with the family, so they often overlooked the disability and completely accepted Kurtis. Kurtis' teacher, however, who is also a community member, mentioned that Kurtis is growing apart from his peers as they age. His ability in community sports is not increasing at the same rate as that of his peers, and a gap is beginning to emerge between them in these activities

> And what happened there is, he grew apart, right? Because it's fine to start with the young children like that, but then they excelled and he didn't excel.

Kurtis has been well accepted in the school environment, according to Lena, by all members of the school community, including the staff and students.

> At school, in the school community, I think he attracts [other playmates] pretty good. He talks to the teachers and talks to the kids. I pick him up at school, and some of the kids will say, "Well, we'll see you tomorrow," and he has the appropriate answers and responses for those things.

Kurtis is able to function socially to his mother's satisfaction, and she is pleased that he can interact in a socially acceptable manner and "get along" with his peers and the school staff.

Similarly, Kurtis' educational assistants also reported that he has been accepted in the school community.

> I think he has great classmates, and they've involved him at play time. He used to be in hockey; they've involved him then. And . . . I'm sure outside at playtime, if [he's] alone, they'll go play with him. He's got a great imagination.

Because of his imagination, Kurtis attracts playmates at recess to play his games. Many children younger than he is enjoy participating in his "imaginary adventures."

In the classroom, Kurtis' teacher added that sometimes he needs to be placed in a group for interaction to take place. Kurtis is not the first choice as a partner for many students, but he is accepted in a group once he becomes a group member. According to his educational assistant, most of Kurtis' social interaction takes place during recess and lunch hour. Sometimes, however, his teacher reported, although Kurtis appears to be playing with other students, he might actually be playing on his own.

> So he has found ways of playing outside around other students so it looks like he's playing, and he's having a wonderful time. But I don't see a friend.

She was concerned that although she viewed Kurtis as accepted by his peers, he was not forming intimate friendships. But according to Kurtis' definition of friendship, the peers with whom he spends time can be considered friends:

Interviewer: What does it mean to be a good friend?

Kurtis: By being nice to your friends.

Interviewer: Being nice. And what do you do to be nice?

Kurtis: By doing some good.

Interviewer: What good things? Can you give me an example?

Kurtis: By playing soccer with them.

In other cases the educational assistants and the teacher reported that other students in the school have taken on a caregiver role with Kurtis: They "take care of him" or "look after him." This is, at times, positive because it means that Kurtis does not always have to look to the educational assistant for help but can ask his peers. At other times, however, Kurtis relies on his peers too much, and the other students will do things for him that he can do independently.

> Well, the students have all grown up with [him] and never had to change classrooms. We're in a small school, and so they are following with [him]. And I remember teachers in the past saying how students used to do everything for [him], and then the teachers have said, "No, you have to allow [him] to answer that question" or "[He] needs to do this."

Benefits of Social Inclusion to Kurtis

In her interviews, Lena identified ways in which she thought Kurtis benefits from his social inclusion. She believes that his social inclusion is preparing him for later life and that he learns skills and behaviour from his peers.

> I think it gives him good and bad. It exposes him to kids that might be teasers so that might be. . .It forces him to make some decisions on his own. He can't just be in this special little group of handicapped kids that are coddled and maybe see things that other kids see. We don't ever want him to be segregated or anything. He learns from the other kids too and from being a part of those groups and stuff.

Lena suggested that interaction with his peers who are not disabled allows Kurtis to function better within his community because he is learning how to act appropriately and react to situations. Furthermore, Kurtis' social inclusion allows him to network, and Lena thought that this could help him in the future.

> The best part about inclusion in school is that he's going to grow up with kids that are probably going to end up and be in business or whatever, and I think that he'll be employable to possibly one of those people. It's all networking and it's all going to be life skills more than anything that's going to get you a job or whatever, and if you stay in a group, you know those people and they know you.

She saw social inclusion as benefiting Kurtis in both the present and the future.

Benefits of Social Inclusion to Others

Lena also discussed how Kurtis' friends benefit from his social inclusion. She explained that Kurtis offers a different perspective to his friends and can teach them about diversity.

> I suppose he'd be a different friend than all their other friends would be because he's not interacting with them as much. He's pretty cut and dried. There's no chit chat, or he doesn't automatically assume things. I suppose they would benefit by maybe noticing that he's different or knowing that he's different.

In addition, according to his teacher, Kurtis adds socially to the school environment. He does special things for his peers, and his peers react positively to his gestures.

> He adds a lot to the classroom socially at times. We have birthday cards; they have to make birthday cards for whoever's birthday is coming up on their own time, and I know the students always appreciate his birthday cards because they're always very unique and have a special message and stuff.

Kurtis has been able to contribute socially in the classroom in a unique way by using his talent and interest in art.

Social Challenges

Lena, Kurtis' teachers, and his educational assistants all described behavioural challenges that Kurtis sometimes faces in the socially inclusive settings. At times Kurtis can be very focussed on a task and not attentive to others around him. His teacher saw this as sometimes a problem after school because Kurtis would rush to get the school bus and at times push other children out of the way. Lena described a similar difficulty when Kurtis is very focussed.

> And I tell him all the time, "When somebody tells you something, you've got to stop what you're doing and talk to them, interact with them. You can't just keep doing what you're doing, because this is how it is."

Sometimes Kurtis would ignore others who were trying to interact with him, which would result in frustration for the other students and isolation for Kurtis. According to his educational assistants, Kurtis can become overfocussed on a task and very upset if he is disturbed; he can get "upset over what we think might be something very minor."

Kurtis can also be very emotionally sensitive or reactive. His educational assistants saw this as being related to his disability because he perceives things differently from other individuals.

> And other children hands-on, touching his stuff, he doesn't like it, and through the years everyone knows that now. But if someone was playing tag and would pull on his coat, well, you don't do that because that's his new coat and you might wreck his coat, and that used to be a really big issue.

This reactivity could again cause others to be less willing to spend time with Kurtis and further alienate him from his peers.

In addition, Kurtis' educational assistants reported that Kurtis at times hesitates to initiate interactions with his peers.

> He will not be antisocial, but he will come into the room all the time and pick a book and will sit and read. And he doesn't always join the group for snack or whatever, but you will find him reading. But that's about the only thing he does: He picks a book and goes and sits. And he will do that in the classroom too.

Relatedly, Kurtis' teacher discussed the differences between the way that Kurtis approaches play activities and the way that his peers approach these activities.

> I think at one time he had friends and they played on the playground. But the play mode got on the silly side, I guess is what the others were thinking, and he is a big boy, and so to play with the Grade 1s and 2s, he would be too rough.

Kurtis seems to have different interests from those of his peers. Because he does not share the common interests of most boys in his peer group, he sometimes has difficulties relating to them. For example, Kurtis enjoys playing tag at recess, but, as his peers grow older, they are less interested in this activity, and Kurtis is often left out of activities because he wants to play tag and his peers want to participate in other activities such as sports. Lena also discussed Kurtis' difficulty in participating in a conversation with his peers: "He wouldn't carry on the same sort of conversation that other boys his age would with people."

Additional to the isolation that he sometimes experiences, Kurtis has also encountered incidences of bullying throughout his schooling. In describing one student in his grade who had acted as bully, he became very animated and angry towards the boy.

> Lena: What else don't you like about school, [Kurtis]? What about [the boy]? Do you want to talk about [him]?
>
> Kurtis: [That boy]! That bully!
>
> Lena: Do you like [him]?
>
> Kurtis: No way! He is such a bully!
>
> Interviewer: Oh no! What does [he] do?

> Kurtis: He is such a bully!
>
> Interviewer: Does he bug you sometimes?
>
> Kurtis: Even his little brother. I hope [they] don't come to school next year! They'll keep making our day worse!

Lena discussed the bully in Kurtis' school in more detail in one of her interviews and told me that this child also has a disability and some behavioural challenges.

> There's a couple of kids that kind of get on his nerves, but they're in the special-ed room too, and so they've got issues too. So I think that's probably part of it. And [Kurtis] can't just hear it and then walk away; that's difficult because he takes everything literally.

Unfortunately, the bullying that Kurtis has experienced has affected not only him, but also his older sister. Kurtis' educational assistant reported that, in the past, Kurtis' sister had become very upset when Kurtis was bullied.

> That would have been three years ago. His sister now is in Grade 8, and she would have been in Grade 6, and there was a bully out there that would say things to [him], but then he'd always say them to [his sister], so it would upset her.

It seems that Kurtis' social challenges affect not only his well-being, but also those closest to him.

Summary

Kurtis' definition of *friend* has three components: (a) someone in close proximity to him, (b) someone who can provide him with assistance in school, and (c) someone with whom he can have fun. Though Lena is not sure whether Kurtis fully understands the concept of friendship, she is pleased that he can function at a socially acceptable and behaviourally appropriate level in both the school and the community. Despite not having the intimacy in his friendships that other students his age might have, he can get help when he needs it. In Lena's opinion this is a very important component of Kurtis' inclusion. Kurtis has grown up in the rural community in which he currently lives and has attended school with many of his classmates since kindergarten, so those around him know him as an individual rather than as a person with a disability. In addition, Kurtis receives support from his immediate and extended family. Despite some sibling conflict, both of Kurtis' sisters support his inclusion at school.

Kurtis does not participate in many out-of-school activities with his friends, but he enjoys structured settings (e.g., recess) in which he can spend time with his peers. He does not enjoy talking on the phone or sharing secrets with his friends but, instead, wants to play games or take part in physical activities such as playing tag. Kurtis' teachers and teaching assistants have been concerned about Kurtis' lack of intimacy with his friends and that he sometimes isolates himself from his peers by taking part in solitary activities. At times on the playground he is engaged in parallel play alongside his peers, with no personal interactions. Upon reviewing Kurtis' definition of *friend*, however, I believe that these are the types of interactions that Kurtis defines as *friendship*. He is satisfied with spending time with individuals in close proximity to him and just having fun; he does not show a need for increased intimacy.

It is also important to note that Kurtis' social inclusion benefits not only him by providing role models and opportunities to network, but also those around him, both family and friends. He offers others a different perspective and awareness of diversity. Also, Kurtis is sincere in his interactions, and when he speaks to his family and peers or makes them a birthday card, the receiver feels a connection with him because he "really means it." Despite any challenges that Kurtis' social inclusion brings, during the interviews it was evident that the benefits far outweigh the costs.

Case Study 3: Nicole (15 years old)

Interview Context

Nicole was interviewed twice for the Inclusion Across the Lifespan project and once for this dissertation project. In addition, her mother, Katherine, and her teacher and teaching assistant also participated in the Inclusion Across the Lifespan project. Nicole presented herself as a very shy but pleasant teenager who seemed to want to please me and would easily become embarrassed if she thought that she was not answering the questions to my satisfaction. Nicole's mother, Katherine, attended all interviews with her, which appeared to bring Nicole some comfort. Her mom would offer emotional support if Nicole was shy about answering some questions and reminded her of certain "happenings" in her social environments. All interviews took place in Nicole's home in whatever setting Nicole felt most comfortable; usually this meant sitting in the living room or around the kitchen table. As the interview process progressed, Nicole became more relaxed. By the third interview Nicole talked openly about her experiences and even asked questions about my own experiences. Nicole enjoys art; because she draws and paints as a hobby, the art-based techniques were a very effective tool during her interviews. Nicole enjoyed drawing the pictures that I requested, and she was able to tell a story to fit each picture. Art is a medium in which she can express herself with confidence. She drew three pictures that represented her social life: one picture of her classroom, one of her favourite leisure activity, and one of her best friend. Nicole drew her pictures with great concentration and was silent during the art-making process. She preferred that I let her finish her picture before I asked her to explain it because she wanted to complete it before she told the "story" behind the picture.

Definition of Inclusion

Like most participants in this study, Nicole defined inclusion as being in proximity to her peers, interacting with the other girls in her school. She feels excluded and sometimes jealous when the girls in her school spend time with their other friends.

> Interviewer: Is there ever a time that you felt left out?
>
> Nicole: Yes.
>
> Interviewer: Just tell me about that.
>
> Nicole: The other girls (when they are hanging out) with their friends.

She does not feel that she can participate with her friends when other friends are present and, to her, inclusion means taking part in activities with her friends.

Related to Nicole's definition of inclusion, her mom, Katherine, also thought that inclusion means spending time with other teenagers. She based this definition on information from Nicole's school and not on her own thoughts on the topic; she reported Nicole's teachers' definition of inclusion.

> I know, for an example, . . . her teacher wanted her to be more included with some of the kids at school, and she liked to be by herself. The teachers are always saying, "Go see your friends; go do something. Don't just sit there by yourself; participate in things."

Like Nicole, Katherine defined *inclusion* as the opposite of *exclusion*. If Nicole is not being excluded or segregated, then Katherine thought that she is being included. Overall, she felt that Nicole is included in school.

> Sometimes maybe not the way she sees it, but I do think that they do try to get her involved as much as possible. And she's more in the class, doing things, participating as a group and as a classroom; where at that other school they would take her out all of the time.

Because Nicole is participating in the same activities with her peers, Katherine believes that she is well included.

Definition of Friendship

According to Nicole, a friend is a person with whom you spend time and to whom you offer assistance.

> Well, if they need something off my paper, like for school, I give it to them.

To be a good friend to her peers she tries to "help them." She also "hanged around them lots" and "talked a lot." When I asked Nicole to draw a picture of a friend, she took great care to draw a detailed portrait of her best friend, Shauna. It was interesting to note that Nicole drew black and white stick figures in all of her pictures except for the picture of her best friend (Figure 8), which she drew in full colour and detailed many of Shauna's physical characteristics. I asked Nicole why she had decided to draw that particular picture in such detail, but she was unable to provide an explanation. Nicole has known Shauna since she was a baby and often talked about the closeness that they share. They did not attend the same school but met because of their mothers' friendship. When I asked what it meant to be a best friend, Nicole described it as being a "good friend." She also explained that she and her best friend shared special things together.

> When we do something together we have a box, then we put that in our box. So if we go to Tim Horton's, we get an extra cup, and we put that in our [special] box.

Nicole seems to share a very intimate relationship with her best friend. She described Shauna as a "great person" who "helps me just be myself." Because Shauna "likes a lot of people," Nicole feels comfortable with her. Nicole not only enjoys taking part in activities with Shauna, but also demonstrates an appreciation for the emotional bond that they share.

Figure 8. Nicole's representation of her "best friend."

Types of Friends

Both Nicole and her mother reported that Nicole has only a few friends and spends most of her leisure time with her mom and her best friend, Shauna. Because Nicole is shy and lacks confidence, she has difficulty forming new friendships and tends to isolate herself. This difficulty will be discussed later in the section on social challenges. Most of Nicole's interactions with her peers take place in the structured school setting, but, according to her mother, she spends time with her best friend outside of school on the weekends.

> Well, sometimes it's every other weekend; sometimes it's two weekends in a row. [Nicole] ended up spending the night there and then she spent two days there. And then again they might not see each other for maybe two weeks, and then they're together again for three or four days, and they're at each other's houses.

Nicole has friends both with and without disabilities. In school her friends tend to be other students with disabilities, most likely because she is in a disability-specific classroom. The peers with whom she is in immediate contact all have disabilities. Nicole had shown some interest in spending time with other students in the school but, in reality, she most often interacts with students from her own classroom. Outside of school Nicole has friends without disabilities who are students from her previous school. According to Katherine, "No matter what, if she doesn't talk to them, they're still friends." In the community Nicole has friends without disabilities with whom she spends time as well, but there is usually an age discrepancy between her and the children she spends time with.

> As far as friends here in the neighbourhood, she's usually around kids that are younger than her.

Activities With Friends

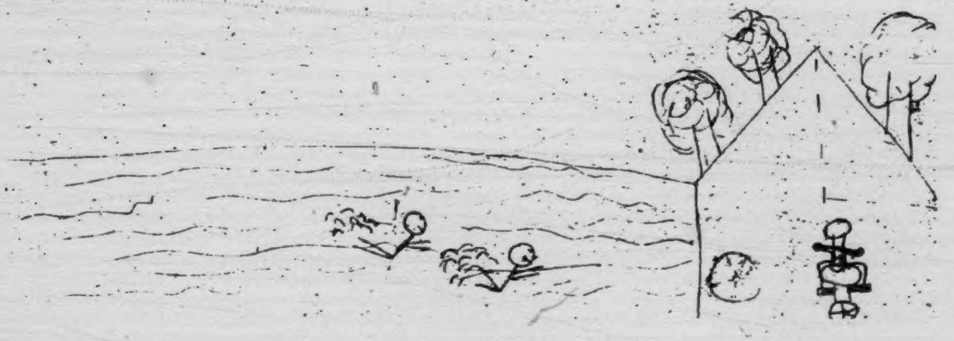
Nicole has visited her friends at their houses on a few occasions, and they will sometimes also visit at her house where they play games, listen to music, and watch television. Nicole reported that these visits do not happen very often and that most of them involve only her and Shauna, her best friend. To keep in touch during other times, Nicole talks to her friends on the phone and over the Internet and sometimes shares secrets with them because she feels that she can trust them.

> Interviewer: Why do you share secrets with them?
>
> Nicole: Because I can trust them.
>
> Interviewer: What makes you think you can trust them?
>
> Nicole: [Thinks] I'm not too sure.

Although she could not explain why she trusted her friends, she just knew that she could trust them.

Other activities in which Nicole likes to participate with her friends are shopping and swimming—again, most of them with her best friend. When I asked her to depict a leisure activity in which she likes to participate, she drew a picture of herself and her friends competing in a swimming race (Figure 9). In the same picture, however, she also drew herself riding her bike alone. I asked Nicole, "Do you like to be with your friends, or do you like to be by yourself?" and, even though she seems to enjoy spending time with her friends, she also stated, "I mostly like being by myself" because "then you can think." In contrast, Nicole reported that she feels lonely at times because there is "nobody to talk to." She seems to prefer a mixture of participating in activities alone and spending time with her friends.

Figure 9. Nicole's representation of her favourite leisure activities (swimming and bike riding).



Assistance With Making Friends

Nicole named two people who have assisted her in forming new friendships, her mom and one of her friends at school. Her mom helps her to make friends by taking her to school and providing her with transportation and support in meeting new people. Similarly, one of Nicole's friends at school has introduced her to other peers and given her the opportunity to meet potential friends.

> Interviewer: Who is that? Who helped you out to make friends?
>
> Nicole: [Brittney].
>
> Interviewer: And is she a friend of yours? What did she do to help you make new friends?
>
> Nicole: Introduced me to the other kids.

Support From Friends

Nicole reported that her friends support her socially and emotionally—that they "just talk," and it helps her. Katherine discussed this support further and stated that

Nicole's best friend, Shauna, provides Nicole with emotional support by accepting her completely.

> [She] has always accepted [Nicole] for who she is and what she is. So even if [Nicole] can't spell things, [she's] there to help her.

Shauna does not make Nicole feel different because of her challenges; rather, she accepts Nicole's limitations and provides the appropriate assistance when Nicole needs it. Moreover, her friends give her opportunities to take part in leisure activities. According to Katherine, Nicole's friends "give [her] someone to do things with other than me all the time."

Nicole's Support of Her Friends

Nicole was reluctant to indicate any support that she provides to her friends. She seems to lack confidence in this area and was not able to identify ways in which she could be of assistance. Katherine, however, replied that Nicole is a good friend and does indeed support her friends.

> [Her best friend] for [Nicole's] birthday wrote . . . a two-page letter stating how great a friend [Nicole] was and how much she missed [Nicole] and how much she just really was a loyal friend and that they could do things, and [Nicole's] always there for her no matter what and no questions asked, and that's what she liked about [Nicole] because she was so giving and so caring.

Relationships With Family

Nicole has a very strong attachment to her mother. Katherine raised her as a single parent and developed a close relationship with both of her children. Nicole was very ill as a child and spent most of the first nine years of her life living in a hospital setting, so Katherine has spent a great deal of time caring for her daughter.

> They figured that she wouldn't make it, and the doctors had told me that she would never walk, she would never speak, she would never really amount to

> anything; just be prepared for that. Well, of course, I love my little girl no matter what.

However, Katherine was concerned that Nicole relied on her for most of her social interaction.

> I've noticed that basically her main source of a friend is me. She calls to me; she looks to me for support for everything.

She sometimes feels overwhelmed by Nicole's dependence on her and confused about what to do because she has worked on developing a close relationship with Nicole but wants to help her to gain independence.

Nicole has an older brother who still lives at home with her. When I asked about her relationship with her brother, she stated that they have a positive relationship and get along "good" with each other.

> He helps with homework sometimes; and if mom's not home, he makes me supper sometimes.

Furthermore, he offers her social and emotional support when she has difficulties with her peers.

> Nicole: If I'm in trouble he helps me.
>
> Interviewer: How does he do that?
>
> Nicole: Like talks to people.
>
> Interviewer: Are you talking about when people bug you sometimes?
>
> Nicole: Yeah.

However, despite the positive nature of her relationship with her brother, Nicole described some feelings of loneliness even when her brother is at home with her, which indicates that their interactions are limited to tasks such as homework completion and meal preparation and do not involve more intimate activities such as leisure.

In contrast to her relationship with her mother, Nicole does not have a close relationship with her father, which involves a great deal of conflict. According to Katherine, Nicole's father "washed his hands from the kids" and sees Nicole only once a year. Nicole does not enjoy spending time with her father and has negative emotions toward him. Her father has drawn attention to her disabilities which, according to Katherine, makes Nicole feel inadequate.

> She doesn't like him at all; she's made that very clear—and considering that he has made it very clear with her disabilities and stuff that she's not normal. He talks to [her older brother]; he does things for [her older brother] differently than he does for [her], which is kind of sad, but she's figured him out completely. She's just, "I don't care for him." When [her older brother] talks about his dad, she'll say, "That's not my dad. He doesn't care about me"

Most of Nicole's male influence came from her uncle who had passed away three years before this study took place. He gave her extra support whenever she needed it.

> Katherine: My brother, who has passed on—he's been gone for three years—he kind of took that role and did things with the kids and kind of disciplined them where I couldn't, or just helped me, kind of thing.

In addition, Nicole has also received male influence from her grandfather and her father's brother. Some of Nicole's father's family continue to have a relationship with her, and she refers to them as her aunts and uncles. Katherine reported that this support helps Nicole to feel that she is a member of the family despite her father's rejection.

> I see different brothers and sisters. He has seven brothers and sisters, and there are some that [Nicole] calls Auntie and Uncle, and they accept us no matter what, so that's still kind of good. And, of course, [Nicole] went to the Christian school where all her cousins went, so her aunt used to drive the school bus and take [Nicole] a couple of times, and she really made us still feel part of the family; whereas some of them, they have just not wanted anything to do with us since we've been divorced.

Other Relationships

In addition to her relationships with her friends and family, Nicole's relationship with her classmates was also a topic of discussion during the interviews. According to both Nicole's teacher and the educational assistant who works in Nicole's classroom, Nicole is generally well accepted in the classroom. She does not appear to have many close friendships in that environment, but her teacher reported that, "generally, the kids are pretty good. We don't have a whole lot of bullying issues or things like that." The teacher viewed any issues that did emerge in the classroom as "normal" teenage interactions. The educational assistant in the classroom reiterated this statement. Nicole tends to isolate herself in the classroom, but her peers generally accept her.

> But as for getting along or not, again, she doesn't go out of her way to socialize with the other girls in the class, but I wouldn't say—for example, she's not a target for the other girls giving her a hard time or anything, so she seems to get along fine that way.

The educational assistant thought that Nicole could form friendships in the classroom if she desired because the other students seem willing.

Social Challenges

The challenge that both Nicole's teachers and her mother discussed in the most detail is the emotionality with which she struggles in regard to her disability. Nicole is aware of her disability and the challenges that she faces, and this causes her a great deal of distress. The educational assistant in her classroom stated that:

> She has more of an emotional problem with being a special-education student than a lot of students I've worked with.

Relatedly, Nicole's teacher suggested that Nicole's awareness of her difficulties has made her self-conscious.

> I think [Nicole] needs to come to terms with the difficulties that she has, and I think then she'll start to progress a little more and that she certainly can make her possibilities for the future a lot brighter if she can get over the self-consciousness. She's never really enunciated why she's self-conscious about it, but she definitely shows that she doesn't want others to know that she has these difficulties. And if she can come to terms with that, I think she can make some big strides.

Katherine also discussed this emotional difficulty and stated that Nicole is "unsure of where she fits in." She displays a desire to be like her peers and becomes frustrated when she notices differences.

> Just before the end of the year with a few girls, these girls are talking about boys and talking about puberty and smoking and doing things. And yes, I think [she] sees that but doesn't really know what to do with that yet, but kind of hears the other girls talk about it: "Why don't I dress like the other girls? And how come I still look like a baby?"

Nicole often refuses to ask for help when she is having difficulties with her school work, which, according to her teacher, results in "silent cries where the tears will just stream down her face quietly at her desk." She is too self-conscious to ask for help and therefore isolates herself and internalizes her frustration.

Nicole identified isolation as an additional social challenge and stated that she finds it difficult to talk to her peers and that she often feels left out.

> Interviewer: I'm not sure if you get recess, but during your breaks, is there anything you find challenging then?
>
> Nicole: Trying to talk to people.
>
> Interviewer: Why do you find that challenging?
>
> Nicole: Because they're always with their other friends, and they're ignoring other people when they're at lunch or a five-minute break.

Katherine reported that Nicole often sits alone at lunchtime even though her teachers make an effort to set up opportunities for social interaction. Nicole frequently refuses to take part in activities and isolates herself. This self-isolation causes a great deal of frustration for Nicole's teacher and educational assistant because they see her as a student with the potential to take part in meaningful, reciprocal relationships. Her teacher stated that, although the school is inclusive, Nicole hesitates to take part in many activities.

> I think [Nicole] would be [included] if she chose to be. I don't think that school excludes [her]; I think [she] excludes the school. So, potentially, it's there for her to be able to be accepted.

Nicole's teacher has attempted to place her in clubs such as a Friendship Club and encouraged her to attend the drop-in room for extracurricular activities at lunch, but Nicole often refuses to participate or comes up with excuses for not participating. The educational assistant in the classroom discussed an example of this behaviour.

> She does know some of the girls that are in her phys ed class, and she knows girls from last year's phys ed class who live in her neighbourhood, so she does talk to them. But I think she sees herself as not being the same as them, and so I think she honestly feels that she doesn't fit with them, because a lot of times the other girls will run off and they'll go down to the corner store or something like this, but [Nicole] will never go—ever, ever, ever. No. She'd say, "No, I'm going to stay in" or "No, I have to heat up my lunch," or "No, I'd rather not."

Nicole's teacher attributed this behaviour to her lack of confidence and awareness of her disability. She also felt that this self-isolation could be part of Nicole's disability. She gets along well with her peers but will often give up or resist further interaction because she prefers to be on her own. Additionally, according to Katherine, in the past some of Nicole's peers have taken advantage of her.

> Because she's such a good-spirited kid, if she has money the kids will say, "Let's go to the store. Can you buy me this?" They might not have that, but [Nicole's] more than willing, and before you know it, her twenty bucks is gone. That's just the kind of kid she is.

Perhaps this past experience also caused Nicole to resist social interaction for fear of being taken advantage of again.

Summary

Throughout the exploration of Nicole's social story, a recurring pattern emerged across numerous themes: Nicole's lack of confidence that has resulted in self-isolation and reduced opportunities for social interactions. Though Nicole does have a best friend and other peers with whom she spends time, her mother and her teachers see her as having more potential to make friendships if she can overcome her self-consciousness about her disability. When I asked her how she helps her friends, she was not able to identify any assistance that she offers them. Katherine, on the other hand, was able to cite meaningful ways in which Nicole contributes to her friendships. It seemed easier for Nicole to discuss how others have helped her rather than how she has helped others.

Nicole does not feel comfortable in a group setting and stated that she feels excluded when her friends are around other people. She prefers to be alone because it gives her time to think but, at the same time, she reported some incidents of loneliness. At school she often makes excuses, such as needing to heat up her lunch, so that she can stay in the comfort of her school rather than going out with her peers. Nicole's teachers have attempted to set up opportunities for her to interact with other teenagers, but "the school doesn't exclude [Nicole], [she] excludes the school." She is even hesitant to ask for help during class time. This is also a concern for Nicole's mother, Katherine, because Nicole wants to spend all of her time with her, and Katherine finds it to be, at times, overwhelming.

In reviewing Nicole's "story," it is important that I acknowledge that during the course of the Inclusion Across the Lifespan project, Nicole experienced a transition in her social relationships. During the last interview with Nicole, Katherine reported that it had been a "turnaround year" for Nicole and that she had really "blossomed" socially.

> She started to be more out with her friends, things that hadn't happened, like starting to take little adventures, having fun with people that she had never met before—just not so much clinging on to me.

Nicole still faces some social challenges, but she has also shown improvement in many of the areas of concern. During the last year of the project, Nicole had a new teacher with whom she developed a bond that seems to have increased her confidence and, according to Katherine, has given her the social support that she needs in the school setting.

> I think she had a really super, super teacher. And I let her know that, that she really made a difference because I know the last two years she was with the same teacher.

Furthermore, Katherine admitted that she just "had to let go" and allow Nicole to be a teenager.

> Yes, I think letting go a little bit too, letting her kind of be a teenager and being where she goes with her friends and just thinking, 'Well, now, got to let her go some time,' right?

At the end of the school year Nicole received an award for her efforts in helping others.

> Katherine: I didn't know anything about it, . . . and she wasn't feeling good. I said, "Aw, well, we don't have to go to this thing." Then her teacher said, "She really has to come. You really need to be there." And [I said], "Well, I don't know because [she's] not feeling good, and we'll see how she feels." And last minute, she [said], "I'm not going." [I said] "Okay." And I get nervous at things like this, so I [said], "Okay, you can just stay at home." And then she said, "No, I think I better go because [my teacher] really said that we need to be there, and [my other teacher] too said you really need to be there." So I [said], "Well, do you want to

> go, or don't you want to go?" "No, we'll go." Well, everybody was getting an award. She burst out of her Grade Nine grad, and a couple of days after, she had this. . . . It was in a really huge church. . . . The church was pretty full. Then they started talking about it: . . . "There's this wonderful little girl. . . . Here's this wonderful girl who's always . . . helped out and always was there and always lent a helping hand." . . . And I'm not thinking nothing, right? And . . . they were going on and on about all these wonderful things, and I'm thinking, [Nicole?]. And I looked at her, . . . and (to Nicole) you weren't sitting there at that time. She was sitting with [her friend]. And I looked at my sister, and I looked at [her teacher], and I looked at [my friend], and I [said], "Did they say [Nicole]? Waahaa! Did they say Nicole?" And they [said], "Yes!" And then all of a sudden I started bawling.

Nicole was very proud of this award and enjoyed hearing her mom talk to me about it. She seems to have made gains in her social functioning and her confidence because of her successes.

Case Study 4: Erica (28 years old)

Interview Context

Erica and her mother were interviewed twice during the Inclusion Across the Lifespan project and two of her employers from the program for children with disabilities were interviewed once. Throughout the interview process I had a good rapport with Erica. Prior to the first interview, her mother, Susan, invited me for lunch so that Erica and I could get to know each other. It was a comfortable setting in which we could interact on a more personal level and begin a conversation about Erica's experience of inclusion. In addition, we are the same age and share many common interests. All of Erica's interviews took place in her home, which was the most convenient location for her. Susan was at home during all of the interviews but would leave the room to ensure Erica's privacy while she was describing her experiences to me. At the end of the interviews, Susan would rejoin Erica and I would give her a summary of our discussions.

During the arts-based interview for this dissertation, Erica was very willing to produce art and chose to use many different mediums (i.e., wax crayons, paint, markers, pencil crayons). She told me that she was used to making art with the children with whom she works, and she was comfortable with the process. As she created her pictures, she told stories about what was happening in each picture and sometimes what happened prior to or following the activities in the pictures. She took great care to add detail to each picture and tell stories as she produced the drawings.

Similarly to Erica, Susan was interviewed in her home and spoke with passion when she described Erica's social experiences. She was willing to express her opinion about the state of inclusion and had many anecdotes to back up her arguments. Susan is a retired teacher who has had experience with other persons with disabilities and seems well educated on inclusion and disability. She has used her education experiences to benefit Erica in any way that she can and is very involved in Erica's social life which, thus made her a powerful informant for this project.

The interviews with Erica's employers took place in Erica's workplace, and I was able to experience the environment in which she worked. Erica joined this interview at the insistence of her employers; they wanted to ensure that she had the privilege of hearing what they had to say about her inclusion in the workplace and to allow her to respond in any way that she felt necessary. They viewed the interview as a learning experience in which they could improve some of their practices.

Definition of Inclusion

Because Erica worked for a program that served children with disabilities, she defined *inclusion* based not only on her own personal experience, but also on the experience of the children with whom she worked.

> Inclusion to me is like being involved in your community, getting to know the people who are involved with helping your child, and also even with other parents to discuss issues in order to help them with their problems or concerns.

She thought inclusion involved interaction with other individuals as well as appropriate supports to meet the needs of the individuals involved.

Erica's mother, Susan, focussed less on the setting in her definition of *inclusion* and defined it with more focus on social interactions.

> I think inclusion to me is offering individuals the opportunity to engage in social work, community activities that they desire to be in, and I think it includes absolutely everything—every aspect of their life. I think it's done basically with minimal support, and it is something I think that should focus on an individual's likes and to some extent their strengths.

She thought that inclusion should span not only school and work, but also the entire life experience. In her eyes, supports are necessary, but individuals should also be encouraged to be as independent as possible and use their own preferences and strengths to take part in events. In addition, she stated that even disability-specific groups can be inclusive in nature.

> I can see that in some ways those [disability-specific] groups to me aren't as segregated as they may appear because they're full of a bunch of different people and the range [is large].

Despite the nature of the segregated social groups, Susan defined them as being inclusive because Erica has been able to interact with many of her peers who have many different abilities.

Both Erica and Susan reported that Erica is well included in her community. Erica stated that she has been well supported in her leisure activities and that special precautions are often taken to ensure that everyone is included.

> [The coaches] wanted to make sure everyone was included in the activities, and sometimes if they want to do an activity, [figure out] how they could help them if they would at least try part of that and not just sit out, because they wanted everyone to have fun. They didn't want anyone to be left out.

Not only does Erica experience acceptance and success in her leisure activities, but, according to Susan, she is also included in the work environment just as any employee would be.

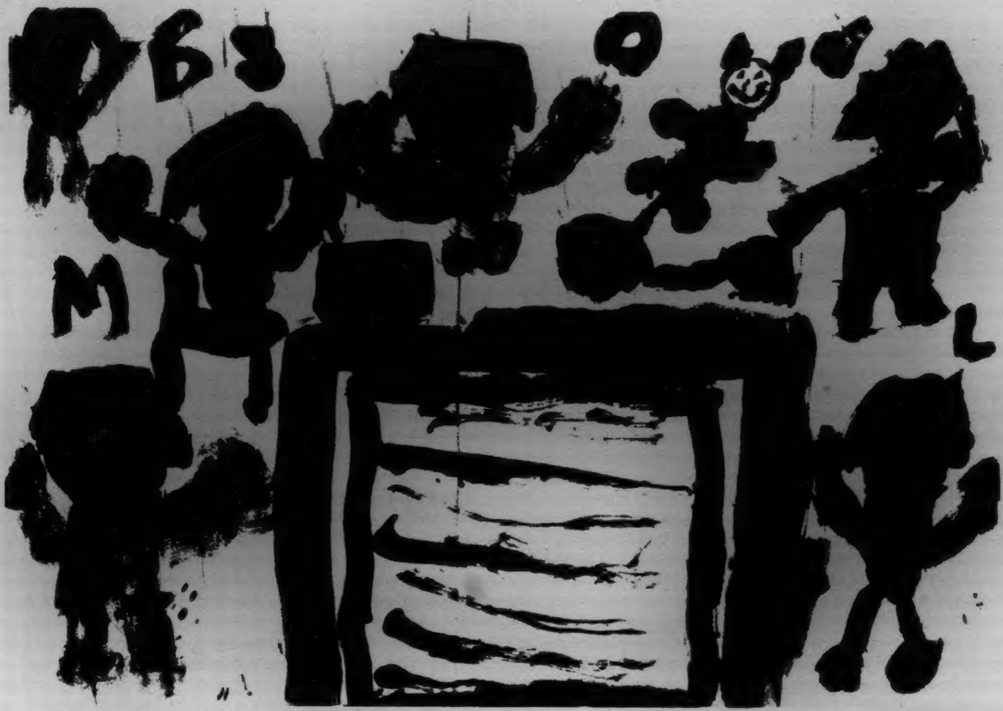
> It's funny, but the staff members get presents as Christmas, whatever, and [Erica] has gotten more presents than I've ever gotten as a teacher! And really nice, thoughtful presents you can tell that the parents put a lot into. So yes, it's been really good.

Erica is always invited to staff parties, professional development workshops, and lunches. The staff at both of her workplaces value her as a staff member and include her in planning activities. She is usually paired with a staff member to run the playgroups at the early intervention program but, when her partner is unable to come to the playgroup, Erica manages it on her own. She discussed this experience and drew a picture of "one of the greatest days" at her work.

> So this is probably one of my best experiences I've had. . . . And my supervisor was just standing back. She wasn't even going to interfere.

Erica drew a picture of herself with the children and the supervisors standing by and observing (Figure 10). She told me that not all of her supervisors were present that day but that she was drawing them in the pictures because they were very happy when they heard about the success of her play group.

Figure 10. Erica's representation of her employment at the program for preschool children with special needs.



This experience was in contrast to the exclusion Erica experienced in junior high school. Two of her classmates in Grade 8 had bullied her, and she described the bullying as making her feel excluded.

> In Grade 8 I didn't feel like I was included because I was always being picked on by two boys and stuff. So I felt that [left] me out a bit, but after the class decided to come to my side. Then it really helped and I felt more included, and I got to go back involved in activities and stuff.

In her discussion of Erica's inclusion, Susan also referred to Erica's challenging experiences in junior high school.

> [Her teacher] decided that [Erica] should do a little in-service about what it was like to be [Erica], called her up in front of the class and asked her to talk about what it was like to have a speech disorder and attend a special school. I never knew about that until one of the mothers of a girl in the class told me that this had happened. And I went to the teacher and I said, "What do you think you're doing? Hello!" With no warning, no nothing! And he said, "Oh, I just thought they'd have a better understanding." . . . And I thought, Oh my goodness, we should have come in here in September. But this was Grade Eight; I thought we'd done all the work in Grade Seven.

This was an "eye-opening" experience for both Erica and her mom. They realized that even with good intentions people might still segregate people with disabilities.

Definition of Friendship

Erica defined a friend as someone to whom she could talk and spend time with. In addition, she felt that trust has to be present for a friendship to exist.

> [A friend is] somebody that listens to you, somebody that wants to hang around with you, somebody that likes to talk to you—just somebody that you can actually trust with telling them stuff; somebody that just won't go around and tell other people.

She stressed that friendship requires some level of intimacy and mutual trust between friends.

> Just that she could come and talk to me if she had problem. She could actually trust me that I wouldn't tell anybody on her.

For a friendship to exist, it is important to Erica that they feel that they can rely on each other for support and have fun together.

> Interviewer: And why do you call him a friend?
>
> Erica: He makes me laugh.

Erica's definition of *best friend* did not differ from her definition of *friend*.

> You would do stuff together. You would hang out with them. And you would also talk to each other.

However, she distinguished between her friends and her best friends. She stated that she did not currently have a best friend because her good friends "weren't ready for that." When I asked for further explanation, Erica told me that her good friends had other friends besides her and that she did not want to tell them that they could not spend time with their other friends.

> Interviewer: And why do you think they're not ready to be best friends?
>
> Erica: Just because they've got other friends but me.
>
> Interviewer: Oh, okay.
>
> Erica: And I don't want to hurt their other friends by telling them that they can't go with them.

She thought that a best friend would have to spend most of his/her time with her and not with his/her other friends.

Types of Friends

Erica said that she has lots of friends—20-25 in her outing group—and that she is getting to know more people through Special Olympics. Both Erica and her mom reported that most of her friends have disabilities. Susan described this group of friends as diverse.

> She gets along really quite well. She has friends that have a wide range of disabilities, so some people that are really quite disabled. There's a person that she did work experience at [a company downtown], and he's in her Friday night social thing. And so, initially, when she started going, because I'm pro-integration, I thought, How can I send her here? But it was interesting, because for her, it put her in a position of being the helper, not the one getting help.

In her outing group Erica has opportunities to support individuals who may be less able than she is and to form friendships with people who are similar to her, but yet different in many ways.

Activities With Friends

When I asked Erica how she felt when she was alone, she stated, "A little scared at first, but once I know somebody is coming back, then I'm okay." She also mentioned times that she feels lonely even when her mom is at home with her, and she prefers to spend time with her friends. Erica reported that she often visits her friends at their houses. She described one incident in which she visited a group home.

> And I did go to one group home, and it was fun. We went to a movie, and then he made me dinner.

She also visits her friends from college.

> I've been to my one friend from college I think three or four times; my other friend from college, once or twice.

On occasion Erica's friends visit her house, but because many of her friends have disabilities, lack of transportation is often a barrier.

> Interviewer: And how often do you have friends over at your house?
>
> Erica: Oh, not very often. Maybe once in a while . . . because it's so hard to arrange transportation.

Instead, Susan provides Erica with transportation to her friends' houses, and sometimes they all meet at the mall or some other community setting to "hang out."

> Interviewer: Where else do you like to spend time with your friends?
>
> Erica: The movies, bowling, going to the mall, just going to their houses and hanging out.

An additional activity in which Erica engages with her friends is talking on the telephone. She said that she does not have many phone numbers but that some of her friends phone her often. She claimed that her friends like to talk on the phone for a long time, but that she tries to keep the conversations short.

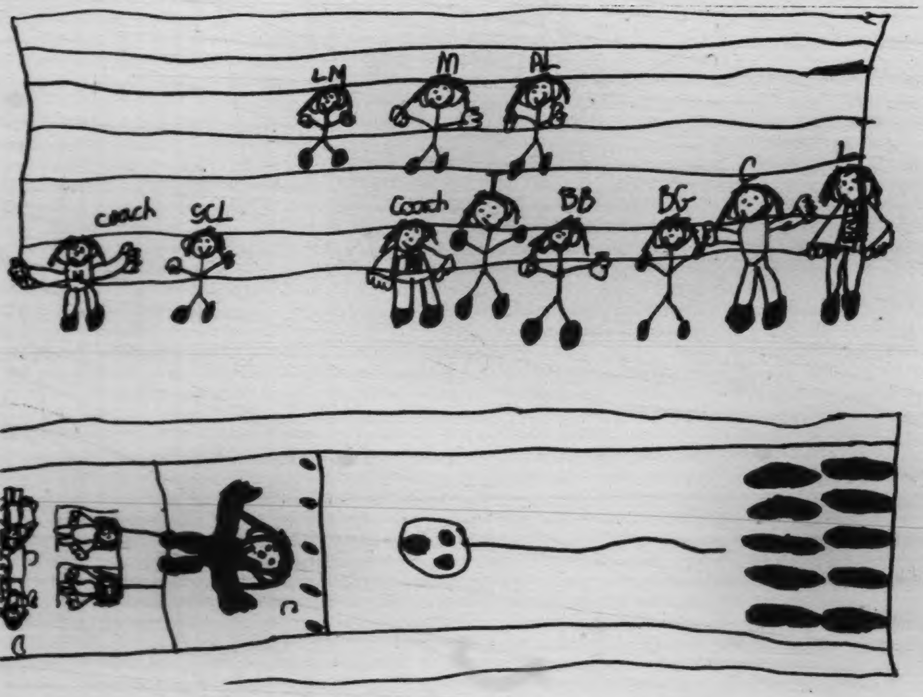
Erica: They can talk forever. Me, I try to make four or five minutes at the most.

Interviewer: And how often do you talk to them?

Erica: Ah, [my guy friend], not very often. And my girlfriend, a lot, because if I don't call her back, she'll call and leave the same message.

When I asked Erica to draw a picture of one of her friends, she asked whether she could draw more than one friend. She drew a picture of her Special Olympics bowling team (Figure 11) and talked in great detail about her experience with her friends at the National Championships.

Figure 11. Erica's representation of her friends at Special Olympics bowling.



Erica: I met her at the tournament, and I also got to know her really well at our training camps.

Interviewer: Oh, for your training camps for Special Olympics?

Erica: Yeah.

Interviewer: Oh, okay. Do you see her very often?

Erica: Uh-uh [negative].

Interviewer: When do you see her?

Erica: At tournaments or if I make a national team. . . . Or if we go to provincials, then we see each other. Or if we make worlds this time, then we will again, but probably not. This is the ball rolling. And these things are finger holes—three finger holes. . . . Do you know what sport we were doing at the National Games?

Interviewer: No. What?

Erica: See if you can tell by the number of pins that I'm drawing when I'm done. This wouldn't be how they're set up. [Laughs] It's just that I don't feel like doing it their way.

Erica explained that the bowling tournament was an exciting experience for her and that she saw many of her friends whom she had not seen in quite some time. She identified many of the parents and coaches who sat in the stands and cheered her on as her friends in addition to the friends who were on her team. Bowling was very important to Erica, and it gave her an opportunity to meet new people and travel to different cities.

Erica discussed the trust that she shares with many of her friends, but she revealed that she does not share secrets with her friends because "it wouldn't be very fair."

Interviewer: Why don't you tell them secrets?

Erica: Because then they just have to run to a friend they know. . . . And then if I run into them, then they feel bad.

Interviewer: Oh, okay. I understand.

> Erica: If I met the person that they told, then they told me what they heard from my friend.
>
> Interviewer: Right, right.
>
> Erica: . . . It wouldn't be very fair.

She was concerned that, if she shared a secret with others, it might become a burden to them, and the feelings of guilt might harm their friendship. This was an interesting finding considering that one component of Erica's definition of *friend* was "just somebody that you can actually trust with telling them stuff."

Assistance With Making Friends

Erica receives support from three main sources when she tries to form new friendships: her mom, her current friends, and the leader of her outing group. Susan helps Erica to form friendships by providing her with transportation to outings and ensuring that the individuals with whom she spends time are safe. Erica stated that her mom needs to "know who I'm with first" before she can go out with friends. Her current friends assist her friendship formation by introducing her to other potential friends who may share her interests.

> Actually, . . . two people who I bowl with, they were in that group, so they introduced me to everybody.

The leader of her outing group plays a similar role.

> He introduces me, and then he just sits there while we talk.

In her outing group Erica has the opportunity to meet new people and is given additional support during the beginning stages of her friendships. Furthermore, she reported that the leaders of her outing group show her peers that "I'm actually a good person to be around." They encourage friendship formation by drawing attention to Erica's positive characteristics and by role-modelling positive interactions with her themselves.

Strategies to Assist Friendship Formation

Erica meets all of her friends in organized settings such as school, outing groups, and Special Olympics (Figure 11). The structure of the settings allows her to gain access to peers who share similar interests, and these settings allow friendships to begin.

> I met [my one friend] at the [bowling] tournament, and I also got to know her really well at our training camps.

Erica told me that, once she meets people and feels comfortable, she then approaches them and introduces herself.

> I'm a little shy at first, but once I gain confidence, then I'll go up and introduce myself.

Following the initial introductions, Erica explained, it is important that she spend time getting to know her peers better so that friendships can form.

> Just by talking and having lunch with them, as well as going to their houses to get to know what they're like.

Support From Friends

Both Erica and Susan described how Erica has benefited emotionally from her friendships. Erica reported that her friends offer her encouragement and emotional support. "They just listen. They encourage other people to try new things." In addition, according to Susan, Erica's friends allow her to be herself and give her the emotional benefit of feeling that she is accepted.

> I think it's a time for her to sort of be herself and to talk about things that they have in common, to share experiences, . . . just to talk about their day and what's been happening. Most of all, I think it's sort of the social-emotional connection of being liked and being with her friends.

The feeling of emotional attachment to her friends has helped Erica to gain self-confidence.

Erica's Support of Her Friends

Not only does Erica receive emotional support from her friends, but she also reciprocates and gives them emotional support. She reported that she tries to listen to her friends and meet their emotional needs when she thinks that they need her.

> I help my friends if they have a question or if they just need somebody to listen to. I just sit with them, and they talk while I listen. And then I give them my suggestions on how to help them after they're done.

Susan confirmed that Erica is a great support to her friends.

> Oh, I think from her sharing all her experiences; I think her enthusiasm and participating in all kinds of activities; her willingness, I think, to be really quite flexible without being [too passive] . . . [still knowing] what she wants to do. I think she's quite accommodating, and I think that she's very warm and caring, and I think she listens to her friends and she tries to support them. So that when friends have had things happen in their family or even with their work, with their job or whatever, I think she's just been there as a really supportive person.

Relationships With Family

Erica and Susan demonstrated a strong bond and seem to have a very positive relationship. Erica's father passed away several years ago thus leaving Susan as a single parent. Susan described the impact of Erica's disability on her personally as increasing her awareness of diversity.

> I think it sort of broadens our horizons a bit. It's also, I think, made me more aware, which is interesting, because before I had [Erica] I was a consultant with the school board, and I used to tell families what to do with their [inaudible] kids. And I thought, My goodness, some of the advice I gave! . . . Oh! And I just thought, Where am I coming from? Little Johnny can't do that and I was [saying], "Oh, I think he can do the route on the playground." And I think it's much different to sort of walk in a parent's shoes as opposed to an educator's.

Susan thought that her experience with Erica had better prepared her for her work as a special educator: It helped her to "be a lot more realistic with parents" and to see the importance of having a parent as a team member.

In contrast, Susan reported that a negative aspect of Erica's inclusion is that it can be time consuming.

> I think that the hardest thing was sort of to always find the time, because initially it was hard. I worked part time, and so every night when we had speech stuff to do and there would be exercises—then, I think, through school, basically it became almost a role of us being tutors to [Erica] because she read so much more slowly than everyone else and she wrote—it took her a lot longer to do things. So I think it was just hard to juggle all that and fit it in and give her the time that she needed for the extra help.

With the extra responsibilities that were involved in Erica's inclusion came increased stress that, at times, was overwhelming for her parents.

Comparable to Erica's relationship with her mother is her positive relationship with her brother, Jake. She admitted that she understands that Jake sometimes wants to be with his own friends, but she enjoys spending time with him too.

> Sometimes it's actually easy because if you have somebody over and it's time to talk with [him], then I don't feel like I get enough time. But I can understand that he wants to go and be with his friends. But usually we get along very good. We usually talk, or we usually just watch hockey or something.

Erica identified her brother as her friend in addition to her relative. Jake provides a great deal of emotional support when she faces a challenge

> He helps me because he can listen to me, and he can also encourage me to try new things. One time he let me try it out on a wakeboard, and I almost did it.

Jake encourages Erica to face new challenges as well as spends time socially interacting with her. She reciprocates this support and "listen[s] to him, and if he wants to do something, I might do it."

According to Susan, Jake is more aware because of his experiences with Erica.

> I think it's made [him] certainly more aware of seeing the strengths in individuals. I think he's much more open to being, not kinder, but more respectful of individuals as individuals, not as someone with a disability.

Jake has learned about diversity and acceptance because of Erica's disability and experiences with inclusion. In the earlier years, however, Erica's inclusion increased Jake's stress because he felt that he had to protect her.

> I think in junior high he was [negatively impacted], and so I think he found himself in the role kind of as protector. But I think as he got older—elementary kids are very nice, very accepting; junior high kids, a whole different ballgame. By the time you get to high school kids are again "people." So I think the junior high years were a little bit more difficult.

Because of his close relationship with Erica, Jake wanted to protect her from negative treatment, and he felt an increased responsibility during his junior high school years.

In addition to the closeness that Erica shares with her immediate family, she also had social ties to her extended family. Susan reported that she did not use respite services because she could always rely on extended family to provide relief care when she needed it.

> There would be some assistance if I wanted it, but it's easy for me to use my family because they're here. So that's sort of the route I've gone. I'm not sure; . . . I don't know if that will change.

Furthermore, Susan explained that Erica receives emotional support from some of her relatives.

> My mom was a big support, huge support for [Erica], and she passed away in 2002. She was probably one of [Erica's] best friends; they just had a wonderful relationship. That was really special. And then after her dad passed away, it was a lot of loss to deal with. The family that's here, my brother and his wife, my sister and brother-in-law, my nieces, . . . they're just there always. When [Erica] got back from her Special Olympics, my brother drove me crazy; he kept saying, "Have you talked to [Erica]? Have you talked to [Erica]?" And I [said], "No!"

Erica's family supports her on many levels, and her relatives seem to be an important part of her life. She even identified many of her family members as friends because they share similar interests and she feels that she can talk to them openly.

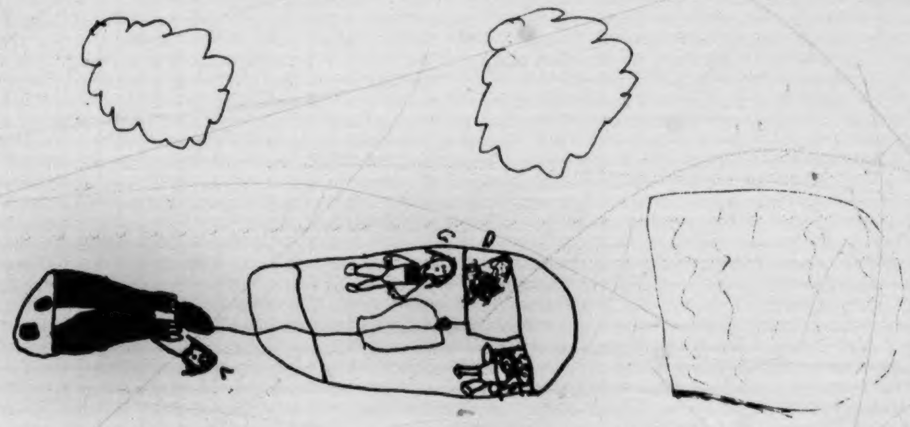
> They like to talk, and most of my cousins on my dad's side of the family, they like to ski. That's how I know them.

When I asked Erica to draw a picture of one of her leisure activities, she depicted a family gathering in which her relatives took her water skiing (Figure 12). She was careful to add details and tell me about the personalities of each individual as she drew them, and she shared personal stories of her social interactions with her family:

> Erica: And now, that's the rope [for water-skiing]. The rope goes out to this bar thing here. And once they played a bad trick on me this year.
>
> Interviewer: Oh? What did they do?
>
> Erica: Start turning the rope to green length [inaudible].
>
> Interviewer: Oh no!
>
> Erica: My cousin and my uncle; they did that to my aunt as well. That's too short.
>
> Interviewer: What happens when it's too short?
>
> Erica: Harder, it's harder to ski 'cause you're closer to the boat.

The personal touches and intimate stories that Erica divulged while she drew this picture indicate the closeness that she shares with many of her extended family members.

Figure 12. Erica's representation of one of her favourite leisure activities (waterskiing).



Other Relationships

Erica talked about her relationships in her workplaces in addition to those with her friends and family. She reported a respectful relationship with her boss and felt that she is valued as part of the workgroup.

> Interviewer: So is the teacher your boss, then, when you're there?
>
> Erica: Mostly, yes. But if she's away, then the aide becomes my supervisor.
>
> Interviewer: And what kind of supervisors are they? Do you like it, or . . . ?
>
> Erica: I like it. Sometimes it's just that they don't always agree with what we do, but still we work it out.
>
> Interviewer: And how do they handle it when they don't agree with you?
> Erica: We talk it out, and when a parent comes out, it's a problem about one of us, then we all talk about it with the parent.
>
> Interviewer: So do you find that the teacher respects you then?

Erica: Yes.

Even if there are disagreements in the workplace, Erica feels comfortable enough to discuss possible solutions with her supervisors. Her main supervisor corroborated this report and views Erica as a co-worker rather than an employee. She stated that they keep the communication in the workplace open so that Erica feels comfortable in giving feedback.

> We always ask [Erica], "Okay, how [did] your morning [go]?" And if she has anything, she gives me feedback for the next time so maybe I can improve some things or I can do it better so she's more successful, or if I forgot about something, so next time I would remember.

Erica's supervisors search for ways to improve their workplace to allow Erica to achieve success rather than focussing on ways to improve Erica's work skills. Furthermore, she is always prepared for her playgroups, and her supervisor reported that she can be relied on to work independently. This independence has helped Erica to gain confidence in her abilities and made her feel proud.

> It makes me feel really good. It actually gives me the chance to work one-on-one. And it gives the aide a break because then she's not doing all the work, 'cause after a while she gets tired of doing the same stuff, and she runs out of neat ideas. but it also gives [the child] the chance to have some fun with his goals.

In addition, Erica's supervisor stated that Erica is good at asking for what she needs. At times the workplace becomes very busy, and Erica must be persistent in her requests.

> [Erica] will need something from us, and she really has to keep coming back and being a broken record on the subject so she actually gets her needs met, because it's hard to nail us down and actually take the time to meet.

Erica feels confident enough in her work setting that she can openly ask for what she needs. This is also the case in the playschool where she works: Although she does not always agree with the teacher and the educational assistants, she can openly tell them that she disagrees.

> Interviewer: How would you describe your relationship with the teacher and the aide?
>
> Erica: Sometimes I don't always agree with what they say, but I do it anyways.
>
> Interviewer: And are you comfortable telling them when you don't agree with them?
>
> Erica: Yeah.

In addition to her relationships with her supervisors and co-workers, Erica also discussed her relationships with the families with whom she works

> The kids like me; they think I'm funny most often.

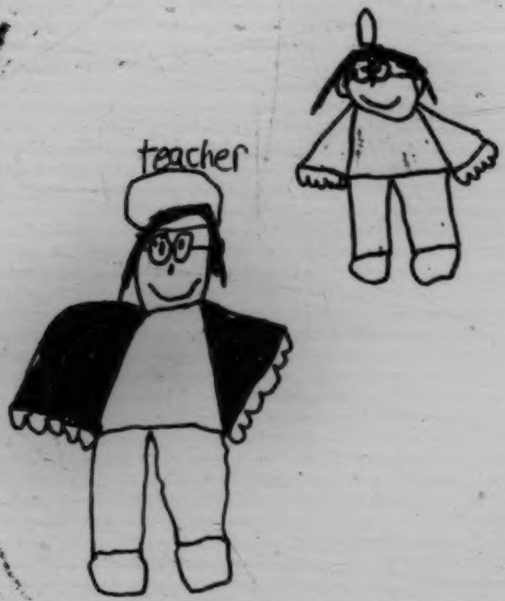
As she drew a picture of the playschool where she works part-time (Figure 13), she told me that the children at the playschool enjoy playing tag with her at recess. In her drawing of her work in the program for children with disabilities (Figure 10), she also described her close relationship with the child she depicted in that picture and stated that he had improved a great deal since she first met him.

> Erica: And [the mom] thinks that [this child's improvement] is because of my work as well as [the aide's] work with him.
>
> Interviewer: So you must be really proud of that.
>
> Erica: Yes. . . . I can see the change, 'cause first year he was not talking at all.
>
> Interviewer: Right.
>
> Erica: And [by the end of the year he] was saying some words.

Interviewer: Yes, that's wonderful!

Erica: He was saying stuff like two-word sentences. So I like to see the change.

Figure 13. Erica's representation of her employment at the daycare.



Because of her effectiveness at work, Erica also has a close relationship with some of the parents of the children with whom she works. Erica reported that the parents often stop by to tell her that she is doing a good job, and she has even received gifts from many of the families at the end of the year. She explained that some parents rely on her for advice because she has had experience with many services for children with disabilities.

> Erica: She would come in to me just to ask me, "Is there anything for him in the future?" What should she do after play school? Should she send him to a special-needs kindergarten or try him in a regular?
>
> Interviewer: And what did you tell her?
>
> Erica: I told her a regular program with an aide in case he needs some help or his friends need to ask something. And I thought if they ask him, he may not feel comfortable talking about it. But if the aide mentions it to them, . . . yeah. And I also told her that there is stuff for him when he's done school, like college programs, university. He can join Special Olympics when he's eight. So if he's interested in sports or anything, he can go there. And she said, "So are there any youth programs?" I told her I didn't know of any, but I knew of some [for] when he [becomes] an adult.

Erica showed confidence in her ability to communicate with parents and provide them with insights into inclusion.

Benefits of Social Inclusion for Erica

When I asked Susan, "What do you think are the benefits of inclusion?" she replied that there are many benefits to Erica's inclusion. Being included in activities has increased Erica's self-concept and allowed her to have many different experiences.

> Oh, I think benefits certainly have a lot to do with just having positive self-concept, giving yourself the power and the strength to do anything you want to do. It just opens you up to new experiences. I think that the more you're with people that are different in any way, you can only just get stronger from those kinds of interactions.

Susan believes that inclusion has "opened up the world" to Erica and has allowed her to become a better person.

> The one thing that I think too is that it made [Erica], I think, a really gently caring person.

Moreover, according to her supervisors, Erica has gained more confidence by working in an inclusive environment. Her main supervisor has seen Erica gaining confidence in her own abilities throughout her time with the organization. If Erica is unsure of something, she has the confidence to ask for help.

> For me [her growth] is definitely that if she isn't sure about something, she would ask us for clarification, and she would ask questions and also share her ideas and bring new ideas, something kind of fresh, and some ideas for our playgroup.

Benefits of Social Inclusion for Others

Erica's employers also thought that others have benefited from Erica's inclusion. Erica works with children with various disabilities, and she acts as a role model and is an example of how individuals with disabilities can contribute to society.

> Employer 1: When [Erica] was reading to the kids, for the parents this would be a precious moment to see how my child in the future can work with children and can be a whole productive member of the society, and that's a dream come true.

> Employer 2: Yes, I think it helps us feel that we're connecting what we talk about with families around why we would want to include their child in their community, why that's a real value of the agency. We're always talking about children having a right to be a member of their community and to go to regular community programs and that if we started in childhood, that it really plays out as a life of community membership at the end of the day, after school. So I think it makes me feel that we're living our message in a congruent way, that we are actually walking the talk of not only, Do we think that it's wonderful for children to be included in the community? [but also] that we've put the bridge right to adult life to say, "And here's what it looks like , and you can have a dream for your child."

Erica's experience has increased the awareness of parents of young children of what is to come for their children as they grow older.

Social Challenges

Erica has had many successes in inclusive settings, but she has also faced several challenges. Despite her many friendships within her social activities, Susan reported that, on occasion, there have been conflicts between Erica and her friends.

> She does really well. Where she has trouble is that some of the girls that are a little bit more boyfriend oriented, they're quite jealous—obsessive. It's like junior high almost, you know what I mean? "Don't talk to him; he's my boyfriend." She has a hard time dealing—she can't understand that, because to her they're just her friends. And that's the only thing. There's been a couple of times where she's had phone calls and it's like, "So and so is saying I'm not supposed to talk to her boyfriend," and [I said] "Oh [Erica], it's okay." But again, because I think they're all socially immature and emotionally a little immature.

Erica has not displayed an interest in romantic relationships; therefore, she cannot understand the perspectives of her friends who have this desire. Erica also discussed this challenge and how it has impacted some of her interactions with her male friends.

> Erica: I got a ten-million-long message yesterday from a guy who liked me, but I don't want to be his girlfriend.
>
> Interviewer: Do you have a boyfriend at all?
>
> Erica: No. He wants me to be his girlfriend, but I don't want a boyfriend yet.
>
> Interviewer: Oh.
>
> Erica: And he's got something for me. [Laughs]
>
> Interviewer: Oh no! [Laughs] And you just want to be friends?
>
> Erica: Yeah, I want to be good friends with him because I'm afraid if I commit to him, then his old girlfriend, who I know, will be jealous.

As a further challenge, Susan also saw a need for more social programs for people with disabilities. She stated that Erica's conversational skills and topics of interest are similar to those of her peers with disabilities and, therefore, that it is important that Erica have further opportunities to interact with these peers.

> But it would be nice for them just to have more things to go to, I guess, and even more mixed things. And I guess that will come with time, but I know that [Erica], she misses her friends from [school]; she really does. And it was interesting because other parents said the same kind of thing.

Without structured activities, it seems that Erica does not have as much opportunity to socialize with her friends.

Another concern that Susan expressed regarding Erica's inclusion in the community is the lack of finances for persons with disabilities: "Getting her AISH [Assured Income for the Severely Handicapped] increased, because AISH is ridiculous" is one of Susan's goals. Erica inherited some money after her father passed away and, because of this inheritance, her government financial assistance had significantly decreased. Additionally, Erica's hours at work were limited because, if her earnings are too high, she will also lose some of her assistance. This financial limitation has been a cause of great frustration for Susan, and she believes that Erica has been restricted because of it.

Another source of frustration for both Susan and Erica is the lack of understanding that some people display toward Erica's disability. Susan described one situation in which a doctor wanted to remove Erica's tonsils but did not think of the consequences of the surgery for Erica's speech.

> Even among the doctors we saw [a lack of understanding]. At one point she had a lot of throat infections and they wanted to take her tonsils out and I thought, Okay, that's great! And I just happened to mention it one day to the speech people, and they [said], "No! No! Because she's learned to speak with the way things are and if you change anything—"

Aside from the medical professionals, Erica also faced a lack of understanding of her disability in her various school settings.

> Susan: A hundred questions and [Erica] got 50 of them done instead of the 100; don't tell me that she only got—
>
> Erica: —30 or 20 right.

> Susan: Yeah, out of 100 when she only finished 50!
>
> Erica: I was going through them as fast as I could.
>
> Susan: But she reads word by word. But in explaining to people—but then the high school was good for your final exam. . . . They get sort of a special request for additional time, use of a computer, a reader, . . . and that worked out.
>
> Erica: I explained I could get extra time, and they wouldn't let me [have it].

Despite the official approval of specific accommodations for Erica, she was at times denied the accommodations because of the lack of understanding of her needs or disability. Erica finds it difficult when people do not realize that she has a disability because her needs are not met.

> Erica: Sometimes they think that I'm a normal person when I'm not.
>
> Interviewer: What do you mean by that?
>
> Erica: They don't think I have a disability when the rest of them actually know that.
>
> Interviewer: And do you find that hard then?
>
> Erica: Yes.
>
> Interviewer: Why do you find that hard?
>
> Erica: Just because if they're asking me why do I do this, what a normal person would do. I actually have somebody that I go out with.

It is important to Erica that others understand her disability to better understand her as an individual.

Summary

Erica has experienced many successes in her inclusion, but not without overcoming some obstacles along the way. Unfortunately, she had to deal with bullying and exclusion during her earlier years that even at the time of the interview still seemed to affect her. In addition, she did not always receive the support that she needed in school. Given her more recent experiences, however, it seems that Erica has other forms of support, such as her family members, who have assisted her in achieving success in her community living.

Erica, her mom, and her employers all described her employment experience as positive for everyone involved, and she is well respected and valued as an employee. The parents of the children with whom she works look to Erica for guidance, and she acts as a role model for children with disabilities. Not only does Erica have a good relationship with her co-workers, employees, and clients, but she has also identified many of them as friends.

Erica has numerous friends in the community as well as at her workplace. Her experience at college resulted in lasting friendships with some of her peers, and she named some of her classmates from high school as her closest companions. Erica has many friends with disabilities, and she is a member of an outing group in which individuals of varying disabilities gather together to take part in community events. Susan spoke very highly of this group and defined it as *inclusive* because there is a wide variety of participants with diverse disabilities and challenges. This was a recurring theme throughout Susan's interviews. She was careful not to define inclusion based on setting but rather on the types of social interactions that take place within an activity. Erica has taken on the role of the "helper" in this group because some of the individuals face challenges that Erica does not. This role has allowed her to gain confidence while, at the same time, building meaningful relationships.

Erica continues to face social challenges that Susan thought might be impeding her social life. Despite Erica's many friends and positive experiences, she still faces some conflict with her friends because, according to Susan, she and her friends might lack the emotional maturity to understand or react to romantic interactions. Also, Erica has encountered financial limitations and negative attitudes toward her disability. These challenges further limit her opportunities, and Susan thought that more special programs should be available for Erica because, if Erica has proper support and opportunities, she will continue to excel in her inclusion and reach her potential as a community member.

Case Study 5: Bonnie (42 years old)

Interview Context

Bonnie was interviewed twice during the Inclusion Across the Lifespan project. She was excited to participate in this project, and we easily built a rapport. She provided me with previous evaluations of her progress in her speech and was anxious to demonstrate how she used her computer to assist with her speech therapy. Between interviews, Bonnie would e-mail and phone me to ask when I was going to visit her workplace. Because this visit was important to her, I scheduled a visit to observe her at the daycare. Bonnie was very excited to have me at the daycare and seemed to enjoy introducing me to her co-workers and the children with whom she works.

During the interview for this project, I asked Bonnie to draw some pictures of her social experiences. She was apprehensive at first but, with some encouragement, soon felt comfortable enough to create some pencil sketches. She would draw a quick representation of her thoughts and then expand on her drawing through verbal descriptions of her experiences. Though her drawings were often simple, they seemed to provide Bonnie with a "jumping-off" point to discuss her social relationships.

All of the interviews with Bonnie took place in the apartment that she shares with her husband Norm. Each time I visited she welcomed me to her apartment and showed me any new needlework that she had done or any new pets that they had bought since my last visit. Bonnie loved her birds and was very attached to them. Sometimes during breaks in the interview, Bonnie wanted to tell me a story about her birds. The interview would easily resume, and we would continue with the questions and answers.

Bonnie's husband, Norm, was interviewed once for the Inclusion Across the Lifespan project. Though Bonnie is her own guardian, I believed that it was important to gain the perspective of one of her family members, and Norm fulfilled this role. He preferred to have the interview in the research office at the university because he was going to be "in the area." Norm is a very social individual and loves to tell stories. He would talk at length about Bonnie's experiences and his opinion on community inclusion for persons with disabilities. Norm stated that although he did not have a disability, he had come to understand disabilities through Bonnie. It was not always necessary to ask him questions during the interview because he felt comfortable speaking and, instead, I tended to use only short phrases to guide him towards a topic rather than asking lengthy questions.

Bonnie's employer was also interviewed during the Inclusion Across the Lifespan project, however, due to the poor quality of the audio file this data was lost. Due to her employer's busy work schedule, no repeat interview was conducted (see Chapter 3 for more detail).

Definition of Inclusion

According to Bonnie, inclusion is defined by acceptance into the family unit.

> Interviewer: What do you think inclusion means? What does it mean to be included?
>
> Bonnie: Just to keep part of our family. When I was born I was very sickly.

Rather than focussing on her peers, Bonnie focussed on her position in her family to define inclusion. When I asked, "Do you feel included in your family?" she replied, "Yes."

Bonnie's husband, Norm, felt that, at present, Bonnie is included in work and in the community as a whole.

> She wants to be not sort of, not outcast, but she wants to be involved with the community. She's involved with choir and stuff like that, so [Bonnie] is now involved in more things.

In the past, however, Bonnie had experienced some exclusion. Norm discussed her exclusion because of her disability when she searched for new job opportunities.

> And then when she tries to get a different job, just for example like a call centre, so, of course, that lady that interviewed her said "Come on in" and then turned against her and said, "Well, you don't have the skills." So, of course, [Bonnie] comes back and says, "Well, how do you know I don't have the skills? You haven't tested me on the computer."

This experience seemed to impact Bonnie's view of inclusion, and, according to Norm, she is sometimes reluctant to include herself in activities because of her past experiences.

Definition of Friendship

When I asked Bonnie, "What is your definition of friendship?" she identified a friend as being someone who provides her with assistance.

> Just like teaching someone to do things. If you have any problems, you go speak to them. They give you information.

She stated that her friends are her friends because "we talk together, and know each other very well." However, she reported that she does not share secrets with her friends because they might choose to tell other people her secrets, and she is not comfortable with that.

Bonnie: 'Cause when they say something to another person . . . kind of thing.

Interviewer: And do you think that happens a lot?

Bonnie: Yeah.

Interviewer: Why does that happen? Why do they do that?

Bonnie: Huh! It's up to them, you know!

It was interesting to note that Bonnie defined her boss and her speech therapist as friends. When I asked her to draw a picture of one of her friends, she chose her former speech pathologist (Figure 14), whom she considered a friend because she helped her with her speech and cared about her progress.

> She's very nice and calm and very concerned about my speech. And she helps me quite a bit with my mouth exercise kind of thing.

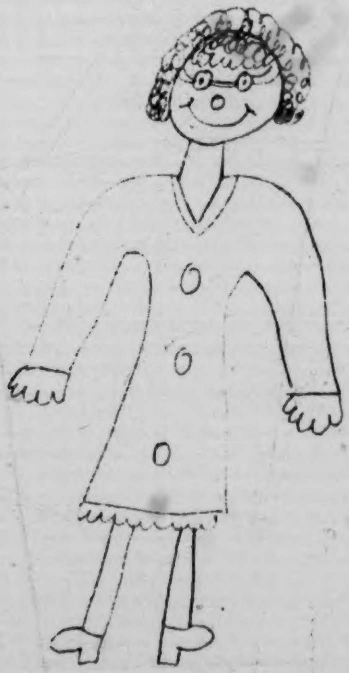
Even though many others would not identify this relationship as a friendship, it did fit into Bonnie's own definition of friendship. She does not see this speech pathologist in person any longer, but she does have e-mail contact with her and still feels attached to her in many ways. She talked about her with compassion as she described the picture she drew.

When Bonnie described her best friend, she also named a former staff member who worked with her, her previous teacher.

> I took courses with her, and after I'm done, I graduate from her course. And then if I have any problems, if I'm looking for some schooling or courses that I want to take, I just call.

Bonnie defined a best friend as "someone who comforts a person, and makes sure they're happy and not sad." Though her definition of *friendship* is similar to her definition of a *best friend*, her definition of *best friend* seems to be focussed more on the emotional aspects, whereas her definition of a friend focuses on assistance with practical skills.

Figure 14. Bonnie's representation of a friend.



Types of Friends

Bonnie reported that she had "a whole bunch" of friends at work as well as in the community. In addition, both she and her husband discussed people from her past who are also her friends. As described in the previous section, many of these individuals are former teachers or support staff with whom Bonnie still maintains contact. Norm added:

> The ones that are close, the ones that have known her for twenty-some years. She doesn't have the newer friends, just close friends, teachers—mostly teachers she stays in touch with. She doesn't have—how do you say?—the droopy friends that go out to nightclubs and stuff like that. She's not like that.

Because most of the people whom Bonnie identified as her friends are former teachers and therapists, most of her friends are individuals without disabilities. However, she stated that a few of her other friends do have disabilities.

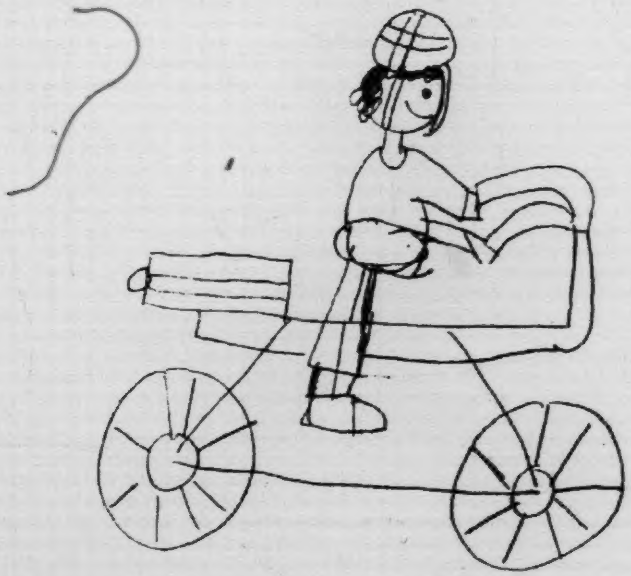
Activities With Friends

Bonnie does not participate in many activities with her friends. On occasion, Bonnie and her husband invite their friends to visit with them at their house, or they will visit at a friend's house. Bonnie also talks on the telephone with her friends when she has time and uses her e-mail to stay in contact with some of her other friends. Bonnie stated that she and her husband enjoy spending time together when they have time off work and that most of their activities are with each other. It seems that Bonnie does not feel that she needs to seek out activities with her friends because she can find companionship in her husband. In addition, she works many hours during the week, and her busy work schedule does not allow her much time to take part in community activities with her friends.

When I asked Bonnie to draw a picture of one of her favourite leisure activities, she created a pencil sketch of herself on a bike (Figure 15). Despite her discussion of the activities in which she participates with her friends (e.g., visiting or talking on the phone), Bonnie chose to draw a picture of a solo leisure activity. She explained that she often rides her bike alone, but sometimes her husband will go for bike rides with her. Her bike is her transportation, and cycling is something that she enjoys. Bonnie stated that she does not mind being alone, but sometimes she would like to be with other people.

> Interviewer: Do you like to be by yourself, or do you like to be with other people?
>
> Bonnie: If it's the fact it's someone who passed away, like if [Norm], my mom and dad, 'cause it's very, very hard to live here by myself, you know.
>
> Interviewer: So if it's a sad time, you like to have people around?
>
> Bonnie: Yeah.
>
> Interviewer: And any other time, do you like to be by yourself then?
>
> Bonnie: Yeah.

Figure 15. Bonnie's representation of her favourite leisure activity (biking).



Even though Bonnie likes to be alone, she sometimes feels lonely.

> I feel lonely, and I want to upgrade my skills. I'd like to do something that I didn't try before kind of thing.

She described how she deals with this loneliness with hobbies such as baking, learning to use the computer, and spending time with her birds. Bonnie is very attached to her birds and talked about them as friends as well. The birds provide her with comfort if no one else is with her.

Assistance With Making Friends

According to Bonnie, she has not received any assistance in meeting potential friends or forming new friendships. During our conversations of friendship formation Bonnie stated, "I do it myself." She appears to be open to speaking with new people she meets and claimed that she does not need help to form friendships.

Strategies to Assist Friendship Formation

Bonnie reported that she met most of her friends at school, and she maintains contact with some of the teachers and students from the segregated school that she attended as a child. She has also met many of her friends at her workplace, which provides her with a structured environment to meet new people.

Interviewer: Where did you meet her?

Bonnie: I met her at [an agency], and I was with her . . . on my lunch break.

Bonnie said that she forms friendships by being in close proximity to other people. For example, she told me how she had met another student who later became one of her close friends because "We caught the same bus together to school."

Once Bonnie meets people, she attempts to form a friendship by going to see them in person or talking to them because she finds it easy to talk to new people. She displayed this skill in our easy conversations.

Support From Friends

Bonnie stated that the main form of support that she receives from her friends is assistance with learning new skills.

She helps me if I have any homework; she helps me do my homework.

Bonnie did not receive formal services from the disability support programs at the college she attended; instead, she relied on support from her friends. In addition, her friends help her with her speech and continue to encourage her when she works on it.

Bonnie's Support of Her Friends

In an attempt to support her friends, Bonnie socializes with them.

Interviewer: How do you help your friends

Bonnie: Have them over or if they want to stay overnight.

Her friends are always welcome at her home, and she makes an effort to be a good hostess when she has visitors. Bonnie seems to enjoy having people visit her apartment. When I visited Bonnie, she always displayed a desire to make me feel comfortable in her home.

Relationships With Family

The family relationship to which Bonnie referred most often in her interviews is her bond with her husband, Norm. She feels secure in her relationship with him and asserted that she can share secrets with him "because I love him." Bonnie participates in most community activities with her husband, such as bowling, attending special events (e.g., festivals), and going for bike rides. Bonnie met her husband through a mutual friend, and they spend a great deal of time together because they share similar interests.

> So I was walking by myself, and I was sitting on the grass watching everything going on kind of thing. And I looked around and I said, "Oh, I know that person" [a friend]. So I walk over and say, "Hi, how are you doing?" kind of thing. And then she was sitting with [Norm], eh? Yeah, so then I asked her, "Do you two want to come over to my place, to my apartment, you know?" And so he did. So we both see how fast we went to my apartment 'cause it's not far from the [festival]; [we] can just walk there, so I walked there. Then we both had coffee or

> tea or snack or treat or whatever at my place. So then we talked, had a chat for a while, and we had some stew.
>
> And [I didn't know whether Norm] was going with [my friend] as just a friend. And then when I asked [my friend] quietly, "[Norm] is your boyfriend or just your friend?" and she says "Just a friend," right? So then, well, we had a chat at our place, and then it was time for her to go home, so we had to make sure she got home on the bus okay. So we had to make sure she got on the bus, and then after that—'cause [Norm] used to live right downtown—so then we walked back to my place and [I asked], "Are you rushed to go home, to get home?" He said "No." So then I said, "Do you want to stay for supper?" He said, "Sure, why not?"

At the time of the study Bonnie and her husband had been married for 10 years, and she reported that they rely on each other for support.

> He's just working so many jobs to support me, and I've got so many jobs. I've got two jobs and supporting him too. So we each have to support each other.

During the interviews she told me that she views Norm as a friend because he assists her when she needs it.

> If I have any things that we can work on, like for homework, he's here to help me.

Norm agreed and acknowledged that he tries to help Bonnie but that, at times, it can be challenging.

> She's climbing that mountain, the top of the peak, and she's not going to go down on it. I mean, it's a challenge, it's a challenge, and it's a challenge. You've got to be the psychologist, the teacher, and the doctor, everything in that household.

It seems that even though Norm wants to support Bonnie, it is important to him that they support each other so that he does not become overwhelmed.

In addition to her relationship with Norm, Bonnie also referred to her relationships with her parents and brothers. She identified her parents and her brothers as her friends because they assist her in many areas.

> I know my mom and dad for a long, long time. And I know my brothers quite well, and they're a friend, too, you know. And if we have any emergencies, we call them.

More specifically, if Bonnie has financial difficulties, her parents assist her financially.

> Okay, . . . how do they support me? . . . If we need any type of money sort of thing, they don't mind paying it for us, and in the future we can pay them back afterwards. This year I had problems with my income tax, and I never paid them so much money, and I'm getting the money back, right? Last year I got some back, but this year I worked two jobs going and my husband has four jobs going, so . . . this year I had to pay like $700 for income tax because my day care where I've got a job didn't take too much income tax off of me, so that's why I got more money this year. But this year where we had to send our income tax to Ontario or wherever they go, we had to make sure we paid them.

Bonnie has three brothers and two sisters-in-law and, according to Norm, she is well accepted by all of her siblings

> She's one of the girls, one of the girls, yes. Well, she's got three brothers on one side, and then my two sisters, so they pretty much get along.

Bonnie confirmed this positive relationship with her siblings and stated that she stays in contact with them even though some of them live in another city. She thought maintaining this contact was a source of support that she provides her brothers with.

> Just make sure they're safe and everything is fine. I phone them, keep contact. Sometimes they phone me.

Bonnie attempts to make herself available to her brothers if they need assistance.

She also reported ways in which her brothers support her. The brothers who live in the same city offer opportunities for socialization and transportation.

> Sometimes I go to their friend's house sometimes, and driving me from there to there.

Bonnie wants to learn how to drive a vehicle but had not had the opportunity to do so at the time of the interview. She thought that her brothers might assist her in learning this skill so that she can become even more independent.

Other Relationships

As described previously, Bonnie has a unique relationship with her birds. She relies on them for companionship when she is alone and talks frequently about her attachment to them. Norm also acknowledged this attachment.

> The connection with [Bonnie] and the bird is so strong. He knows her so well after eleven years. A bird is so smart. He's just—he'll talk to her; he'll talk to her in his own language, and they're characters. You come home and you put on some music, and there'll be whistling and whatever.

Bonnie's pets are an important part of her life, and she and her husband have strong emotional ties to them. Norm described how difficult it was for Bonnie when one of her birds became ill.

> Oh yes, that put us to tears, and we called her father—I mean, we called her dad over, and he didn't have any questions. We called all the vets, and the vets told us the wrong words. They told us—instead of saying "Yes, we will help" they said, "Oh, just bring him over and we'll get rid of him," meaning—so it was the wrong word from the vet, and he said, "No, no, I don't mean that way; I mean get rid of him as in—" "How?" "Oh, well, we'll just—" "Oh, no, no, I don't think so." And I had to stop right there and think, "Okay, get rid of him. Meaning what? Give him the needle of gone." And I said, "No, no, he'll make it." And we just sat up, and we had candles, and we just prayed, and we were crying.

Bonnie's faith helped her through the loss of her pet, and Norm discussed her use of prayer as a form of coping.

In addition to her faith, Bonnie finds social support within the church community. She attends choir practice as a form of speech therapy and finds that, within this group, she is able to form social ties within the community. She also attends regular church services and met some of her peers there.

> Interviewer: How does going to church help you
>
> Bonnie: Meeting a bunch of people. I have one, . . . my mom and dad's friends' daughter, and she's like a big sister to me kind of thing.

Because she attends church with her family, she has met her parents' friends and [illegible]lizes with them and their families.

[illegible] of Social Inclusion for Bonnie

When I asked, "What are the benefits of inclusion for you?" Bonnie felt that her inclusion is important because it gives her opportunities to better herself

> It just gives me more skills and more learning.

At college Bonnie learned numerous practical skills; she is eager to learn and displayed an interest in taking more classes in the future. I asked her, "Would you like to take more classes sometime?" and she said that she would like to go back to college and take the next level towards her early childhood development certification. Bonnie also enjoys attending workshops and seminars to gain additional information. At the end of the Inclusion Across the Lifespan project, Bonnie attended the wrap-up information session organized for the participants and affirmed that it was a good learning experience.

Social Challenges

Bonnie discussed social difficulties that she sometimes faces and described one particular challenge that concerns her: her difficulty in being assertive.

> Bonnie: Anything difficult? Yes, it's hard for me actually. I talked to my tutor and she's going to work with me on it. It's problems—I tell my mom and dad about it too—I just have to be— . . . I have to talk things out with somebody, and I'm kind of scared, and I hate to hurt somebody's feelings, And if a person doesn't do their job, I hate saying, "You can clean this. This is a job for cleaning" kind of thing, And if I have problems I go see my supervisor, and she can be in the room at the same time; she can be in this room, so I have to be by myself and some other lady. And . . . so that's what I need to work on.
>
> Interviewer: So you find it hard talking to people when you need them to do something?
>
> Bonnie: Yeah, I hate to make them upset or mad. So I have to work on that.

Bonnie is a senior staff member at her workplace, but, despite her experience, she lacks the confidence to tell junior staff members what needs to be done. She is afraid that they will not listen to her or that she will cause conflict if she is assertive. According to Norm, her co-workers sometimes question her or tell her she is approaching a task in the wrong manner, and Bonnie does not have the confidence to be assertive in her response.

> Oh, yes, they'll tell her, 'No, don't—oh, you're doing that wrong' or 'Don't warm up the bottle this way.'

At times Bonnie's lack of confidence has even resulted in lost opportunities, as Norm explained:

> Well, at one time she was just in the babies' room, and she wanted to go higher up, work with the toddlers or the preschools, but her verbal words, they weren't coming out as clear, and the mother or the children would say, "I don't understand that word." And probably babies are different than the toddlers and the preschool, so probably the disciplining is different for her. She's not a "Sit down! Be quiet!" She's not a mean one. Probably at work it's different; she's got to be tougher.

Even though Bonnie has the desire to try new positions and new experiences at work, she is not confident in her ability, which makes her unable to discipline the children appropriately.

Norm described incidents from Bonnie's past that may have affected her self-confidence. During her schooling Bonnie was bullied by some of the students at her school because they saw her as different.

> And [Bonnie] has been there in a way that you can't really describe her. She was looked at in school in a different level of kids. They would say, "Oh well, I'm not going to be your friend because you're at a different level" or "the way you look," or "You're three hundred pounds" or whatever the case may be. "I'm not going to be your—" And even now—not now, but the kids I've heard it get like that as well, so it really hasn't changed. People looked at her disability in a way, "You're different." But they treat you different.

More recently, as I was leaving Bonnie's apartment, she described another incident of bullying that she had encountered only a few weeks before. Her bike had been stolen from her apartment complex, and the light from her bike was smashed on the sidewalk in front of the building. This distressed Bonnie because she could not understand how someone could do such a thing. This incident seemed to further damage Bonnie's self-confidence because she did not know what she had done to deserve having her bike stolen.

Furthermore, Norm also felt that Bonnie does not always receive the necessary support in her inclusion, which has resulted in frustration and a lack of confidence.

> So she gave her a test of so high proportion that she totally—I don't know the word—just didn't believe what she was saying, and she thought she could go into, say, just for example, [college] for a level two, and then the teacher and another colleague would say, "Well, you need English." So she went to the course and she paid it, and it was so difficult because she never took the test to enter her into the level. So she did go, but the teacher never balanced her out with all the others. The students were at a higher level and she was at the lower level, and the teacher never understood that at the time way back when. Everybody just got into the school, do the course, and get done.

According to Norm, while Bonnie was attending college she did not receive the accommodations that she needed to perform to the best of her ability. Relatedly, Bonnie reported that she struggles in a large group setting and finds it easier to learn when she is in a smaller group, but she was not provided this opportunity.

> Bonnie: If I'm in a big group I don't get into anything, like [inaudible] in the classroom.
>
> Interviewer: Do you find it hard to fit into a bigger group, or what do you find hard about having a big group?
>
> Bonnie: A big group is just too much, I can't hear. I can hear; it's just, if I'm in a small class I'd be okay; if I'm with a big classroom, it's hard for me.

With this lack of support, Bonnie began to see herself as less capable than her classmates, which again decreased her confidence.

Summary

During my exploration of Bonnie's social experiences, two main categories of relationships emerged as important components of her social life: family relations and former support staff. The importance of these relationships was a recurrent pattern in Bonnie's interviews and across many themes. Norm is an essential social support for Bonnie; he provides her with both material and emotional support and attempts to increase her confidence. Bonnie's main social challenge is her lack of confidence, which has prevented her from pursuing some goals and desires. Norm encourages Bonnie in her ventures and increases her self-confidence. Bonnie and Norm support each other and share intimate secrets because of the trust that they have built in their relationship.

Other family members also play an important role in Bonnie's life. She and Norm both include their pets in their family. Bonnie is very attached to her birds and relies on them for companionship when she is alone. Additionally, discussions of Bonnie's immediate and extended family revealed close bonds within the family unit. Bonnie is well accepted in both families and relies on them for support if emergencies arise. She tries to return this support by making herself available to her siblings if they need assistance.

The role of former support staff members in Bonnie's life is very important. She has maintained contact with many past teachers and therapists and defines several of them as her closest friends. Although she has other friends in the community from such settings as her community church, most of the conversation about her friendships centred around individuals who once played a paid support role in her life. Though many individuals would not identify people in these roles as *friends*, they do fit Bonnie's personal definition of *friendship*. She described a friend as someone who provides assistance and emotional support, and her former staff members filled both of these roles. She did not always have adequate academic support in college but could rely on these friends to assist her if she encountered difficulties. Many support staff members assisted Bonnie with her homework and speech, which enabled her to graduate with her college diploma. Bonnie thought that it was important that she attend college and other workshops in the community because it helped her to gain skills. However, she admitted that she could not have done this without the support of her husband, her family, and her friends.

Case Study 6: Lyle (63 years old)

Interview Context

Lyle was interviewed twice for the Inclusion Across the Lifespan project. In the first interview he appeared to be very nervous. He was concerned about providing the "correct" answers and had to be reassured throughout the interviews that I wanted only his perspectives. After receiving this encouragement, Lyle stated that he enjoyed spending time with me and asked to go for a cup of coffee so that we could visit more. He wanted to use my car to go to a nearby coffee shop, but because I do not have the proper insurance on my car to transport passengers, we agreed instead to have coffee in the cafeteria in his apartment building.

All interviews with Lyle took place in Lyle's apartment, which was where Lyle felt most comfortable in talking about his experiences. During the Inclusion Across the

Lifespan project, he lived in a senior citizens' apartment complex that also contained a program for persons with disabilities. He had his own living quarters but could eat his meals in a community dining room and watch TV with his peers in the shared recreation room. At the time of this dissertation research, Lyle had moved to another apartment building because he wanted to live more independently and did not want to be part of a program. He does, however, still receive support from the advocacy agency with which he has been involved for years.

The interview for this project took place in Lyle's new apartment, and he seemed proud to show me his new home. Lyle was reluctant to draw any pictures, and when I asked him to draw, he sat in silence, staring down at the blank page and holding a felt pen. He seemed to want to please me by drawing the pictures, but he did not have the confidence to do so. After a few minutes had passed, Lyle looked up from his paper and said, "I don't know." I asked him whether he wanted to draw, and he said "No." At this point we abandoned the arts-based techniques, and I conducted a regular open-ended interview.

In addition to interviewing Lyle, I also interviewed his sister and a staff member from his advocacy group for the Inclusion Across the Lifespan project. I spoke to Lyle's sister, Doris, twice at her home. Like Lyle, she was shy at first but seemed to relax as the interview progressed. After a few questions about Lyle, Doris began to open up about her own experiences with him and described the frustration that she sometimes feels as his sister. She also talked at length about her concerns with the general treatment of persons with disabilities in society.

I interviewed the staff member from Lyle's advocacy group because Lyle did not work at paid employment but, rather, volunteered at the advocacy agency, which thus made this staff member also his employer. She was not able to provide me with details regarding Lyle's inclusive experiences, but discussed some of Lyle's challenges and cued me on some topics that I might want to discuss with Lyle. This prompting assisted me in preparing the questions for my next interview with Lyle.

Definition of Inclusion

Lyle defined inclusion as many of the participants in the other case studies had; to him, inclusion means being with other people.

> Interviewer: What does it mean to you to be included?
>
> Lyle: You mean included with everything?
>
> Interviewer: Yes. What does that mean?
>
> Lyle: You mean like when I go out with people and all that, to be included?

In addition, he was able to describe specific incidences in which he had felt included in an activity.

> When we go out sometime, we go to meetings or something. I have to take [my friend] to, [we go by ourselves]. We just went to a meeting [downtown]. I forgot which hotel we went to. And we went to that, and . . . I took care of [her] because we had lunch there, and it was some kind of meeting for [my organization]. And then we went there and we had lunch.

Many of Lyle's stories of inclusion included structured activities that assisted him in spending time with others. The agency that supported him offered several of these activities.

Lyle's sister, Doris, also defined inclusion as spending time interacting with others, but she focussed more on interactions within the family unit rather than interactions with other people in the community.

> Well, to be part of the family—which he is—for the main family events and everything. Our friends we're very close to because both my parents are dead, so my best friend's son graduated from Grade 12 and he had an eighteenth birthday party. We all went to that. So things like that that he's included in—being part of the family.

Most of the activities that Doris described as inclusive to Lyle involved family or close friends. She repeatedly stated that Lyle is included in the family and described efforts that she has made to include him in all family celebrations such as the birthday party that she described above.

Definition of Friendship

Lyle defined *friend* based on the actions of his friends towards him. To him, a friend is someone who "let[s a friend] talk sometimes and don't interrupt and talk when you're spoken to, and all that." In addition, a friend is someone who offers help when he needs it.

> Friend means, if you have a good friend, you can talk your problems or something like that.

The help that Lyle described was more emotional than physical or materialistic in nature. Similarly, in discussions of best friends, Lyle described his best friend as someone who provides him with support as well.

> She's always there for you. Like, I can go over there. . . . I have breakfast there with her in the morning around 9:30, and then we have coffee. And I have my supper there all the time with her. And then I do the dishes and pots and pans after for her.

His relationship with his best friend seemed to be more intimate than his other friendships. Lyle smiled as he talked about his best friend and described how they spend time together every day. To him, his best friend is someone with whom he can have fun and rely on for emotional support at any time.

Types of Friends

Lyle described himself as not having many friends. During several points in the interview he talked about wanting to meet more people.

> I don't have many friends—just [Joe] and [Tom] and [Lindsey]. We go to dance every Wednesday, but I'd like to meet some people to go out for coffee or go to a movie or something. . . . I'd like to meet some people—like the public, you know?

Even though he showed this desire to meet others, he stated that he "does pretty well" and does not often feel left out. He talked about activities with his advocacy agency in which he feels included and often referred to his friends who live in the same apartment complex as he does. On the other hand, he admitted that he does feel lonely on occasion.

> When you don't have nothing to do or nothing, . . . you just sit at home sometimes when you don't have nothing to do. Or you have no—[my friend] goes out. . . . Your friends are all busy. You don't have anybody; you just sit home.

Although Lyle stated that he is not always lonely, he sometimes feels lonely when he is not with other people. Furthermore, he sometimes finds it difficult to keep busy and find activities in which to take part. In contrast, he stated that sometimes he did not mind being alone.

> Sometimes I like to be on my own. . . . Sometimes I'll go to [the mall] myself. Sometimes I'll go have breakfast there myself. Like, to go be myself sometimes, by myself. And then I go there and spend half an hour at the restaurant having coffee, reading the paper.

Lyle seems to like spending time with his friends but not all of the time. When he is bored, he wants to know that others are accessible to him so that he can socialize.

Most of Lyle's friends are persons with disabilities. He met the majority of his friends through the senior citizens' complex in which he lived or through the agency that provides him with support. Lyle stated that he does not have any friends that he met elsewhere but, as stated previously, would like to meet other people in his community.

Activities With Friends

Despite reports of not having many friends, Lyle was able to describe several activities in which he took part with his friends. He visits his friends at their homes and, on occasion, has them visit him at his home. Lyle goes to his friends' homes about twice a week and then invites them to his apartment about once a week. One exception is his best friend: Lyle visits her at her house every day because they eat supper together. They live in the same building, and she also frequently visits him at his place.

Lyle reported that he talks to his friends on the phone almost every day for periods of 15 to 20 minutes at a time. The conversations with his friends are at times intimate, and Lyle feels that he can share secrets with his friends because of the trust between them that allows him to share intimate thoughts.

> And I do [share secrets] once [my friends] go around. If you tell someone you have a problem you don't want nobody to know, and then they won't tell anybody, you know. Like, they'll keep it secret, you know?

In addition to these regular social activities, Lyle also participates in some special activities with his friends. One of his favourite community activities is going to restaurants for coffee or a meal; he finds places that are inexpensive, which allows him to participate in this activity frequently.

> We like to go to the [casino] for breakfast on Saturday morning. They have a special all the time. We have a card, and it's only $2.99 for lots of eggs, orange juice and coffee, but you have to get there early, from nine to twelve. Yeah, we go there every Saturday.

In addition, Lyle enjoys taking part in special events such as dances or guided tours. He goes on several day trips each year with his close friends.

> For Christmas, December third, we're taking tours. . . . [My friends] are going too. It's like a Christmas musical.

Lyle seemed to value theses activities because they give him something to do in his spare time and provide him with opportunities to interact with his peers.

Assistance With Making Friends

Lyle has received help with making friends both as a child and as an adult. As he was growing up, he learned social skills from his teachers.

> Interviewer: And where did you learn how to be a good friend?
>
> Lyle: From school.
>
> Interviewer: So your teachers told you how to be a good friend, did they?
>
> Lyle: Yeah. That was a long time ago.

Even during a time in which students with disabilities were segregated in special-education settings, Lyle learned friendship skills.

More recently, he has relied on his support staff to assist him with friendship formation.

> [My worker] helps me. Like, we meet, and, like, I met [Danny]. I met him, like the first time; he was shy and I was shy. We went out at [the mall]; we had lunch together. He got to know me a little bit, and, and then we got to go like once a month or once a week. We went Denny's restaurant or Boston Pizza or something like that; once a month or once every three weeks we go have a meal there.

Lyle's support personnel have helped him to meet potential friends and have set up structured activities in which he can interact with his peers.

Strategies to Assist Friendship Formation

According to Lyle, he met his friends at parties and special events, usually those organized by his advocacy group. He stated that he would introduce himself and try to get to know the people at the events.

> You try to meet friends like at parties and at get-togethers and going out with other people, and you just go say, "Hi, I'm [Lyle]." And then they say, "Hi, I'm _______." And that's how you meet them. Then you talk to them all the time, and you get to know them all.

Lyle seems to need a structured setting to meet other people. After the initial meeting takes place, he then attempts to start conversations with individuals by discussing common interests.

> Interviewer: And what do you do to start a friendship with somebody? What are some things that you do?
>
> Lyle: Talk.
>
> Interviewer: Talk about what sort of things?
>
> Lyle: What's on their mind. And "what do you like to do, and you like to go out?" If there's things to do, and all that.

Lyle reported that he often asks to meet his friends for coffee and talks to them about what they like. This is the strategy that he has used most frequently to form friendships with his peers.

Support From Friends

When I asked Lyle, "How do your friends support you?" he stated that his friends provide him with emotional support.

> They usually help me because when I have a problem [with something] I can talk to them.

In the past, because Lyle had had difficulties with depression and emotional disturbances, this support was very important to his well-being. In addition, he reported that socializing with his friends makes him happy.

> And we go there for breakfast, and I go with [two friends], getting out for Sunday morning, you know. Take the bus down there, and it feels good to get out. Just stay there for an hour, and it feels good.

Lyle's friends do not necessarily have to provide him with any specific supports; just spending time together with them improves his emotional state.

Lyle's Support of His Friends

Lyle displayed a great desire to assist his friends in any way that he can because helping others brings him a sense of satisfaction. Some of his friends with disabilities also face physical limitations, and Lyle is able to assist them with these needs.

> Helping people get around to their [appointments] . . . like, I take [my friend] down every Monday and Thursday, like for our programs. She goes on [the bus], and I help out other people around.

Because Lyle does not have a formal occupation, his work is helping others.

> See if they need assistance on things and all of that. That's what I do.

It is important to Lyle to be needed, and he often seeks opportunities to assist his friends. During the interviews he displayed pride in his ability to assist his friends, and it seemed to be a source of confidence for him.

Relationships With Family

Lyle and his sister, Doris, described their relationship in a positive light. Lyle stated that he gets along well with his sister, and Doris reported that they are very close to each other. She told me that her relationship with Lyle has helped her to become a better person.

> Oh, I think I am who I am because of [Lyle]. . . . I think I'm a more compassionate person.

She also described how her relationship with Lyle has helped her daughter, who is "drawn to handicapped people" because of Lyle, and Doris sees this as having a positive impact.

However, Doris stated that her relationship with Lyle sometimes increases the stress in her life.

> It would have been easier to have a normal brother or sister

She always wished for another sibling in addition to Lyle because she would then have someone to share her responsibilities with. Doris talked about the emotional struggles in her relationship with Lyle.

> Oh yeah, guilt all the time. Yeah, I feel a lot of guilt. Well, actually, I just got over it when I was in my forties; I'm in my fifties now. I always felt guilty because I got much more than Lyle.

This emotional response to her relationship with Lyle lasted many years despite her loving relationship with him. She attempts to assist Lyle in many ways and ensures that he is provided for. Doris and her family offer Lyle financial support to ensure that he can participate in activities that he likes and buy items that he wants. Lyle mentioned this support several times during his interviews.

> [Doris] helps with finances sometimes, like if I need extra money for something, like on trips or something like that. We just went to [the city] and she paid for all that, but I had spending money. But I saved up spending money, eighty dollars, so I had that. But she paid for the hotel and the food, so that's good. So I had my own room and everything was air conditioning, and everything was nice. And we went to the family reunion on Saturday, and then Sunday we went to church.

Other Relationships

In addition to his family and friends, Lyle also discussed his relationship with his support staff. One staff member has provided him with one-on-one life skills training and support in leisure activities. Despite this person's paid position, Lyle identified him as a friend.

> Interviewer: And do you call [him] your friend then?
>
> Lyle: Yeah.
>
> Interviewer: And why would you call him a friend?
>
> Lyle: He's good, good.
>
> Interviewer: And what does he do? Why do you say that? What makes you say that he's good?
>
> Lyle: Because when he has a night, he always asks, like, if you want to go bowling or play pool or go there. And then he picks you up, and then we go have fun.

Lyle values this relationship and depends on his support staff for a large portion of his social activities. He also identified some of the staff in the agency who support him as friends as he often goes to the agency's office to socialize over a cup of coffee. Staff members have played a large role in Lyle's social life.

Lyle also told me that he goes to church on a regular basis and has formed relationships within the church community. He attends church with his sister and brother-in-law, and Lyle's sister described the role that Lyle plays in church.

> But when he does [go], he sits in the back. He does the collections, and everyone speaks to him and they're very encouraging and they're always happy to see him and they're always saying what a great help he is and things like that. He makes coffee. When he didn't come with us, he would go early and make coffee for the choir and the ministers. But he comes with us now, so he doesn't do that. And helps with coffee after church sometimes. When we do coffee, he will help.

The church congregation values Lyle, and he played an active role within the community. This acceptance helped him to gain confidence and provides opportunities for further social interactions. Lyle also described the important role of the church in his life.

> You see people there, and . . . I help people at the church too sometimes, setting up on Sunday when it's the [inaudible]. I set up the chairs and everything for ministers, and then when there's coffee downstairs, when there's something else going on like a luncheon, help them make the luncheon and drinks and help serve the food.

Benefits of Social Inclusion for Lyle

Doris sees benefits in Lyle's social inclusion. She feels that he is a better person because he has been included in regular community activities.

> I think it helps him not be so much self-centred, kind of spoiled. And I do think, [his friend], he takes care of her, and I think he feels really good about that—kind of taking care of her and bringing her treats I think he really likes that.

According to Doris, Lyle was more selfish in a segregated setting, but his inclusion has taught him that at times he has to assist others. This also helps him to gain confidence in his abilities.

Lyle's inclusion has also taught him essential life skills that have helped him to form additional social relationships. Doris reported that inclusion "keeps him wanting to be clean. . . . There was a time he went through where he wasn't very clean." Because Lyle has role models for appropriate social behaviour in inclusive settings, he has learned socially acceptable ways to look and behave. In the past, when Lyle was segregated, he did not attempt to behave in a socially appropriate manner; but since his inclusion in the community, he has learned that to be accepted he has to be hygienic. Moreover, Doris believes that Lyle functions at a higher level when he is with higher functioning individuals and that integration with nondisabled individuals has helped to "keep his brain active."

Social Challenges

During his interviews Lyle suggested that he faces some social challenges, but he had difficulty articulating them aside from stating that he wanted to meet more people. However, Doris described his social challenges in more detail. Lyle struggled early in his life because he had some awareness of his disability; he knew that he was different from his peers and it negatively affected his self-concept.

> Well, I think he always [saw himself] as a dummy. I think that bothered him because he's smart enough to know he was not smart. And they picked fun at him because he couldn't do gym—I think he had to do gym. . . . We didn't go to the same high school because my high school didn't have a special class. So I think . . . a lot of [his] problems are coordination, and they poked fun at him because he couldn't do gym and things like that. I think he took gym with the regular kids.

Lyle was teased because of his disability, and this exacerbated his negative self-perceptions.

An additional challenge from Lyle's past that also caused him to withdraw socially was emotional distress. Following his mother's death, Lyle became depressed and, on a few occasions, attempted suicide. This not only resulted in a lack of social interaction, but also put additional stress on his family. Until her death Lyle's mother was his caretaker, and after her death Doris felt that he was not prepared to live independently.

> I don't think [Mother] really prepared him growing up. I felt very overwhelmed with the responsibility of him.

This challenge, however, improved over time, and Doris said that, because Lyle can cope well on his own now, she does not feel as much responsibility for him.

A more current challenge that Doris discussed was Lyle's lack of interest in participating in certain activities. She explained that it was difficult to go on vacation with Lyle because he wanted to take part in only certain events.

> Doris: He goes on vacations. We took him—and I don't think we'll take him again . . . .
>
> Interviewer: Oh, really?
>
> Doris: Well, it's not that he's difficult; he just wants to eat, and he doesn't walk, you know, so it's hard for us.
>
> Interviewer: It's limiting?
>
> Doris: He's very limited, so he goes on those day trips. He doesn't have a whole lot of money. We paid for everything, so for [him] it would just be to go somewhere and to sit and eat. And . . . his group was going to [another city on a field trip], and he wanted to stay there and stay in a hotel, and they said, "Well, if you just want to stay in a hotel, why don't you just go to [a hotel here]?" So he went to [a hotel here], and he stayed in a hotel and he paid a lot of money, and then he just walked around and went to restaurants and stuff. For him to go on a big vacation, it really is not that important of place.

Doris viewed this challenge as limiting Lyle's social interactions because he does not attend many events in which he can meet potential friends. Furthermore, this is a challenge for Doris because at times it makes family functions difficult and frustrating.

Relatedly, two additional challenges sometimes prevented Lyle from participating in some social activities. First, he is unable to walk long distances because of his physical limitations.

> Interviewer: Do you exercise?
>
> Lyle: I can't. . . . It's . . . I don't know. . . . It's hard.

Lyle is overweight, which limits his mobility and prevents him from attending certain events. Not only is his ability to walk long distances affected by his obesity, but, according to Doris, so is his ability to be transported in his family's vehicles.

> And I said, "If you're fat, we can't lift you." He broke one seat; . . . the car is no longer—we don't have it any more. But he broke our front seat because he [inaudible]. So we got our new car—it's not new any more. We made him sit in the back seat, and we tried to get him to get in properly and to sit down properly, and we told him—he had problems getting out of the car, and we said, "You know, if you gain any more weight, people won't be able to drive you."

The other challenge that at times prevents Lyle from participating in social events is a lack of financial resources. Sometimes he does not have enough money to fully participate in events.

> I was going to go to [the fair], but last year when I went there, it cost too much. I took fifty dollars with me, and it was gone in five minutes. The food is expensive. Everything is so expensive there.

Lyle's sister also discussed Lyle's lack of money for leisure activities and told me that she sometimes gives him extra money to take part in a desired activity.

A final social challenge that Doris identified is Lyle's occasional inappropriate behaviour. She is deeply concerned about his eating habits and fears that, without proper table manners, he will not be fully included socially.

> He has very, very annoying eating habits. I find all of [the people with disabilities in his building] do, and I talked to them there about it. I said, "You know, he's obnoxious sometimes when he eats." His teeth don't fit right, and he just shoves it in his mouth. And we were having pizza one night, and he had so much put in his mouth that a piece came out. So I always notice that when we go to some of the dos there, but [he] is probably one of the better ones. So I said, "Aren't they encouraged to have better table manners?" And so [a staff member] says to me, "Well, you know, we don't like to say anything because we control everything else; we don't control their eating habits." Then I didn't say anything, and I thought, talking about inclusion, if you want them to be included in your family and for people to invite them out to meals and everything, they should have good table manners. So it was very stressful for us for [the family reunion], because we ate three meals a day, most of them out, just the reunion for the birthday party. He was there, and we found it very . . . it's almost obnoxious. And I don't know; . . . I don't think that's necessary.

Lyle's poor eating habits have caused his sister and her husband a great deal of distress, and they find it difficult to include him in their social circle if the event is centred around food.

Summary

To both Lyle and his sister, inclusion means spending time with others. Lyle reported incidents of inclusion with his advocacy agency, but he still feels that he is not fully included in the community and spoke often about wanting to "meet more people." Lyle does not have many friends in the community aside from paid support staff or other clients with disabilities who live in the same apartment complex. It is relatively easy for him to become friends with these individuals because he has structured activities such as agency meetings or parties that allow him to have access to his peers in a supportive environment where he can build relationships. Lyle does at times venture out into the community, but he often does this alone, with his support staff, or with his friends who have disabilities. Lyle's support worker has played a large role in assisting him in setting up social activities. Independently, Lyle's only strategies to initiate social interactions are to introduce himself and talk about common interests. In school he learned how to build relationships, and even though he seems to have an understanding of the mutuality of friendship, he discussed these strategies in general terms and did not seem to have an in-depth understanding of how to apply them successfully.

Lyle helps his peers in any way that he can and takes pride in this role. However, he seems to have difficulty in more intimate interactions, especially with individuals without disabilities. Lyle grew up being self-conscious about his disability and, according to his sister, has had a keen awareness of his differences. This self-consciousness has resulted in a lack of confidence in his interactions with others, which might be one reason for his difficulty in forming friendships outside of his agency or apartment complex.

In addition, Doris discussed Lyle's physical limitations and lack of motivation, which limit his social activities. She thought that, if Lyle would be more willing to take part in a diverse array of activities, he might have more opportunities to meet other people. Doris finds it difficult to take Lyle out to events because he is not always willing to take part. Also, Lyle's eating habits concern and embarrass Doris, and she thought that they also limit Lyle socially because others might not want to eat around him.

Lyle has a strong desire to have friends in his life and enjoys the support he receives from his friends. He also enjoys giving support and spending time with others. However, he seems to understand that he faces challenges in his social inclusion and becomes frustrated by this. Lyle's challenges also frustrate Doris because she has seen many ways in which Lyle has benefited from social inclusion. He continually makes an effort to be socially included in his community but is not always successful in his attempts.

CHAPTER 5: DISCUSSION

Introduction

In the previous chapter I presented a snapshot view of social inclusion from the perspective of six participants of different ages. Within each case study are discussions of social relationships, social supports, and social challenges for these individuals with developmental disabilities. In this chapter I will revisit some of the themes as I compare the case studies and look for similarities and differences across the cases (see Table 4 for a summary of cross-case comparisons). In addition, I will discuss my findings in the context of pertinent literature on the topic of social inclusion. To summarize, I will present practical considerations and future directions for policy and practice.

Discussion of Results: Cross-Case Comparisons

Definition of Inclusion

All participants defined *inclusion* as being in close proximity to or in the same activities as other people. Both the participants and their parents/guardians described inclusion as "being with peers." Within these definitions, several different settings were discussed. For example, Kurtis (12 years old) discussed his social inclusion in school while his parents discussed his inclusion in the community as a whole. In further contrast, Erica (28 years old) and her mother discussed Erica's inclusion in her outing group that consisted of individuals of varying disabilities. This is consistent with Abery's (1997) definition of social inclusion as social relationships that "transcend specific settings or contexts" (p. 4). This is not to say that setting does not play a role, but it does indicate that it is not just the environment that constitutes inclusion; social relationships must be present.

Definition of Friendship

All participants defined a *friend* as someone who provides assistance and support and a *best friend* as someone with whom the participants spend a great deal of time and share special "things." Stephanie (6 years old) did not define friendship in this manner herself; instead, her mother discussed the important role of friends in her daughter's life. According to Nancy, Stephanie would define a friend in more simple terms such as a peer with whom she plays while Nancy, herself, would define a friend as "someone that I know is always there and just always a part of my life, and you can always rely on, and just kind of someone through thick and thin." This finding demonstrates a pattern that was consistent across all cases: The parents tended to describe friendship in more intimate terms than their children did. Some of the participants discussed closeness with their friends in terms of actions or behaviours (i.e., "just like teaching someone to do things. If you have any problems, you go speak to them, they give you information" [Bonnie, 42 years old]), but the parents often identified a psychological intimacy, like that described by Stephanie's mother. In fact, in Kurtis' (12 years old) case, his mom discussed her concern about how Kurtis' definition of friendship differed from her own.

> See, I don't really think he really knows what friends do. He knows that they help him at school, but he doesn't have the same sort of relationships with a friend that other kids do I think maybe . . . he doesn't seem to need that like the other kids.

According to Heyne (1997), friendship is an emotional and psychological connection between two people in which (a) the friends freely choose each other, (b) the friendship is mutual and reciprocal, and (c) the friendship is expected to endure. It is not based solely on actions and behaviours, but also requires affective attachment. Within the case studies, these three aspects of friendship emerged. Nancy, Stephanie's mom, described friends as individuals that "like each other;" they are not forced to be friends rather they choose to be friends. Moreover, both Nancy and Erica (28 years old) discussed the mutuality of friendship. Nancy described friends as sharing "common interests" while Erica (28 years old) stated that, not only could she rely on her friends, but that "[my friend] could come and talk to me if she had problem. She could actually trust me that I wouldn't tell anybody on her." With respect to an enduring friendship, Nicole (15 years old) described her best friend and the fact that they have been friends for an extended period of time. They had met as toddlers and their friendship was still strong over 12 years later. It seems that, though the participants described their friendships based on activities and actions, they were still able to describe the three aspects of friendship as outlined by Heyne (1997). Perhaps, to the participants, friendship meant something slightly different from what their parents/guardians were describing, but their definitions can still be identified as *friendships* nonetheless.

Another notable difference among the various definitions of *friendship* was evident between the three youngest and three oldest participants. Stephanie (6 years old), Kurtis (12 years old) and Nicole (15 years old) described *friends* as individuals with whom they take part in activities or, according to Nicole (15 years old), "hang around" with. However, Erica (28 years old), Bonnie (42 years old), and Lyle (63 years old) discussed friendship in a more detailed manner that included specific behaviours that friends' display toward each other. For example, Lyle (63 years old) described how his friend cooked supper for him and Bonnie (42 years old) stated that her friends helped her with her speech therapy.

Friends With or Without Disabilities

An interesting finding emerged when I explored the descriptions of each participant's friends. All of the participants have friendships with both peers with and without disabilities but, within their descriptions of friendships, Stephanie's (6 years old) mom, Kurtis (12 years old), Nicole (15 years old), and Erica (28 years old) tended to focus on their relationships with both their nondisabled peers and peers with disabilities, whereas Lyle (63 years old) focussed on his interactions with other persons with disabilities. One explanation of this finding is that Lyle (63 years old) attended a special program for persons with disabilities while the other participants were exposed to both peers with and without disabilities through school, work, and leisure settings. For example, Erica (28 years old) attended an outing group for individuals with disabilities but she was also employed in a "regular" work environment in which she interacted with numerous nondisabled peers. According to Nancy, Stephanie (6 years old) had mostly friends without disabilities with whom she went to school, but one of her classmates also had a disability and Stephanie formed a friendship with her because of shared experiences and challenges. Friends with disabilities appeared to play an important role in the lives of the participants and gave them a sense of confidence. In both Erica's (28 years old) and Lyle's (63 years old) cases, having friends with disabilities allowed them to provide assistance to others in need rather than their being only receivers of assistance, a concept that is largely overlooked in the current literature. Most previous studies aimed at exploring only the social relationships of persons with developmental disabilities and their nondisabled peers but have not considered the role other persons with disabilities play in the environments. In the studies in which segregated placement is discussed in the literature, many researchers describe it as having negative impacts. For example, Elliot and McKenney (1998) and Johnston (1994) described the stigma that students with disabilities placed in specialized settings have to contend with. These findings are not, however, consistent with the participants reports. Erica (28 years old), Lyle (63 years old), and Stephanie's (6 years old) parents/guardians all describe the importance of being allowed the opportunity to interact with others with disabilities. In fact, Lyle and Erica both benefited from specialized programs by helping others in need and gaining self-confidence. Zemke et al. (1984) supported this notion and found that participation in a camp program with peers with disabilities showed a significant increase in the individuals' overall self-concept.

As a third category of *friendship*, Bonnie (42 years old) described former support staff and teachers as her friends. Instead of focussing on her peers when discussing her friendships, she, instead, described her best friends as being former therapists. These support-staff relationships are consistent with Bonnie's (42 years old) personal definition of *friendship:*

> She's very nice and calm and very concerned about my speech. And she helps me quite a bit with my mouth exercise kind of thing.

These relationships also seem to complement what the most recent literature has reported. Test et al. (1993) found that support staff in many socially inclusive workplaces provide several social supports to persons with disabilities. These supports include explaining schedules, talking about life, caring about their clients, providing reminders, obtaining special equipment, and introducing the person with disabilities to potential friends. In addition, according to Birenbaum and Re (1979), support staff often initiate social activities for persons with developmental disabilities. Without this support, the persons with developmental disabilities take part in fewer social activities. Positive relationships between individuals with disabilities and their support staff is a key element of successful social inclusion (Recchia & Lee, 2004). In fact, as in Bonnie's case, support staff relationships can often move "beyond dichotomous caregiver/carereceiver labels" (Pottie & Shumarah, 2004, p. 64) and result in meaningful, mutual, long-lasting friendships (Luttfiya, 1990).

Activities With Friends

In the discussions on leisure activities, the two youngest participants, Stephanie (6 years old) and Kurtis (12 years old), seem to have a need for structured social activities (e.g., planned play dates, school activities); whereas the remaining older participants, Nicole (15 years old), Erica (28 years old), Bonnie (42 years old), and Lyle (63 years old) have found success in unstructured activities such as talking on the phone or just "hanging out." All participants discussed the personal importance of special events in their lives. Whether it was Special Olympics, birthday parties, or community events, each participant discussed his/her enjoyment in taking part in such activities and looked forward to upcoming events. Pottie and Shumarah (2004) found similar results in their analysis of the L'Arche communities: special events such as birthday parties played an important role in the social lives of their participants.

Table 4

Summary of Cross-Case Comparisons

Topic	Case (all perspectives)					
	Stephanie (6 years old)	**Kurtis (12 years old)**	**Nicole (15 years old)**	**Erica (28 years old)**	**Bonnie (42 years old)**	**Lyle (63 years old)**
Definition of inclusion	Being with others Individual support	Being with others	Being with others	Being with others	Being with others	Being with others
Definition of friendship	Someone who provides assistance Spending time together Best friend – same as any other friend	Someone who provides assistance Spending time together Best friend – deeper bond	Someone who provides assistance Spending time together Best friend – deeper bond	Someone who provides assistance Specific social behaviours Best friend – deeper bond	Someone who provides assistance Specific social behaviours Best friend – deeper bond	Someone who provides assistance Specific social behaviours Best friend – deeper bond
Friends with or without disabilities	Focus on friends without	Focus on friends without	Focus on friends without	Focus on friends with	Focus on former support staff	Focus on friends with
Activity with friends	Special events Need structured activities	Special events Need structured activities	Special events	Special events	Special events	Special events
Assistance with friendship formation	Mother Support staff	--	Mother Other friends	Mother Support staff Other friends Need structured activities in beginning	Need structured activities in beginning	Support staff Need structured activities in beginning
Support received from friends	Social/emotional Skills assistance	Skills assistance	Social/emotional	Social/emotional	Social/emotional Skills assistance	Social/emotional
Support given to friends	Social/emotional	--	Social/emotional	Social/emotional	Social/emotional	Physical
Impact of disability on parents	Increased stress Increased awareness	Increased stress	Increased stress	Increased stress Increased awareness	n/a	n/a
Impact of disability on sibling	n/a	Learning opportunity Logistical challenges	Learning opportunity	Learning opportunity Emotionally challenging	n/a	Learning opportunity Emotionally challenging
Support received from parents	Social/emotional	Social/emotional	Social/emotional	Logistical	Logistical	n/a

(table continues)

Topic	Case (all perspectives)					
	Stephanie (6 years old)	**Kurtis (12 years old)**	**Nicole (15 years old)**	**Erica (28 years old)**	**Bonnie (42 years old)**	**Lyle (63 years old)**
Support received from siblings	n/a	Physical	Physical Social/emotional	Social/emotional	Social/emotional	Financial
Support given to siblings	n/a	Physical	--	Social/emotional	Social/emotional	--
Extended family support	Emotional	Emotional	Emotional	Emotional Respite	--	--
Other types of relationships	Community members Babying from peers	Community Members Babying from peers Rural Advantage	School Relationships	Work relationships	Work relationships Church community	Church community
Benefits of social inclusion to participants	Learning opportunity Networking opportunities	Learning opportunity Networking opportunities	Learning opportunity Increased self-confidence	Learning opportunity	Learning opportunity	Learning opportunity
Benefits of social inclusion to others	Learning opportunity	Learning opportunity Social benefits	Learning opportunity	Learning opportunity	--	--
Social challenges	Self-isolation Bullying When to inform child and others about disability	Self-isolation Bullying Different interests from nondisabled peers	Self-isolation Bullying Lack of confidence	Lack of essential supports Bullying Lack of confidence Different interests from nondisabled peers	Lack of essential supports Bullying	Lack of essential supports Self-isolation Lack of confidence Physical challenges

Assistance With Making Friends

The participants in this study identified three essential forms of support in helping them to form relationships: parents, other friends, and support staff. Stephanie (6 years old), Nicole (15 years old), and Erica (28 years old) all reported that their mothers had provided them with opportunities to interact with their friends, which thus indicated that this maternal support did not end in childhood but also continued into adulthood. Previous research has supported this finding that mothers are able to facilitate positive social interactions (Bhavnagri & Parke, 1991; Keachie, 1997; Ladd & Hart, 1992). With parental assistance, the children with disabilities have more positive social outcomes (Keachie, 1997). As a second form of support, Nicole (15 years old) and Erica (28 years old) explained that their current friends had introduced them to additional potential friends. Thirdly, Erica (28 years old) and Stephanie's (6 years old) mom considered support staff or teachers important resources in forming friendships. This finding complements those in previous studies focussed on the role of support staff in the lives of persons with disabilities. As described in the previous section, Birenbaum and Re (1979), and Recchia and Lee (2004) found that support staff often initiate social activities for persons with developmental disabilities. Support staff can provide a safe environment for social interactions to occur, thus encouraging further relationship building.

Contrary to other participants' claims of assistance, however, Kurtis (12 years old) and Bonnie (42 years old) reported that nobody assisted them in forming friendships. As Day and Harry (1999) found in their research on two adolescent girls who built a close friendship during their time together in school, it is close proximity to peers over time that has allowed these participants to build lasting relationships. No formal supports were needed for these two individuals to form a friendship aside from being provided with opportunity to interact with their peers.

When I explored the strategies for friendship formation in more detail, it was interesting to note that all of the participants stated that their personal strategies were to introduce themselves to their peers and try to learn more about these potential friends. Even after some probing during the interviews, these were the only strategies that were reported by the participants themselves. When I interviewed Stephanie's (6 years old) mother, she asserted that social-skills training to ensure that persons with disabilities "know what it means to be a friend" is of utmost importance. Erica (28 years old), Bonnie (42 years old), and Lyle (63 years old) all named structured activities such as meetings, parties, or conferences as important components of friendship formation. The structure within these settings helped them to overcome any social-skill deficits that they might have and provided an opportunity for them to meet and interact with their peers. Once they have formed friendships, these three participants can then take part in unstructured activities such as "going out for coffee" (Lyle, 63 years old), or "hanging out" (Erica, 28 years old); but they first need a structured setting for these friendships to begin. Previous literature has focussed on structured settings such as church (McNair & Swartz, 1997; Trulear, 1997), work settings (Test, Hinson, Solow, & Keul, 1993), and home environments (Pottie & Sumarah, 2004) to examine the benefit of structured social settings for persons with disabilities. According to McNair and Swartz (1997), many church settings provide an atmosphere of acceptance that allows opportunity for peers to meet in a "safe" environment. Similarly, Test, Hinson, Solow, and Keul (1993) found that many social inclusive work environments provide opportunities for persons with developmental disabilities to interact with and form friendships with their co-workers. Finally, in the home environment, Pottie and Sumarah (2004), found that supported home settings like L'Arche often emphasize frequency of contact with peers to provide further opportunities for the persons with disabilities to interact with their peers and form lasting relationships.

Support Received From Friends

All participants in this study considered their friends' social/emotional support an important contribution to their lives. For example, Nicole (15 years old) described how her friend "just talked" to her and helped support her. Nicole's mom, Katherine, also described the emotional support Nicole received from her best friend.

> [She] has always accepted [Nicole] for who she is and what she is. So even if [Nicole] can't spell things, [she's] there to help her.

This is a benefit of friendship that has been acknowledged in previous research. Reidy (1993) reported that friendship provided persons with developmental disabilities with a personal sense of fulfillment and belonging. In addition, Heyne (1997) states that friends support each other through sharing affect, support, companionship, and compassion.

As an additional form of support, three of the participants, Stephanie (6 years old), Kurtis (12 years old), and Erica (28 years old), described how their friends provided them with physical assistance when they needed it. This physical assistance is essential in ensuring that natural interactions occur without unnecessary interference from support personnel or parents. While this important form of support seems intuitive, previous research has largely overlooked it.

Support Given to Friends

Like the support that they receive from friends, the participants also described the social/emotional support that they give to their friends. Stephanie (6 years old), Erica (28 years old), and Bonnie (42 years old), as well as Nicole's (15 years old) mother, discussed how they are able to return the emotional support that their friends offer them. It is interesting that even the youngest participant, Stephanie, reciprocates this emotional support by "looking out" for her friends and "tell[ing] someone if it doesn't look like someone is having fun" (Stephanie's mom, Nancy). In Lyle's case (63 years old), he cited offering physical support as an additional method of helping his friends. He has many friends with physical disabilities to whom he can provide assistance such as pushing their wheelchair or reaching for items from a shelf. While some researchers acknowledge the benefits that friendships with persons with disabilities can have on the peers, such as being provided with a role model that has faced challenges (Myers (1991) or gaining increased awareness of diversity (Wolery & Wilbers, 1994), no research has acknowledged the personal benefits such as those listed above.

Another interesting point in this category is that, when Kurtis (12 years old) and Nicole (15 years old) were asked "how do you help your friends?" they stated that they did not know. Kurtis was entering early adolescence and Nicole was currently in mid-adolescence; past literature has suggested that this lack of awareness of how one may help one's friends may result from the social awkwardness of this adolescent developmental period. Roid and Fitts (1988) found that as preadolescents enter the adolescent years, their self-perceptions become more negative, and they feel lower self-worth. There seems to be a systematic decline in self-esteem during the early adolescent years (Marsh, 1985). Self-esteem begins to rise, however, as late adolescence and early adulthood emerge (Block & Robbins, 1993; Fleming & Courtney, 1984; O'Malley & Bachman, 1983; Zimmerman, Copeland, Shope, & Dielman, 1997). This finding is consistent with my findings in the cases of Erica (28 years old), Bonnie (42 years old), and Lyle (63 years old). The adult participants viewed themselves as individuals who could, indeed, provide support to their friends. For example, Erica (28 years old) stated that she provided support to her friends "if they just need somebody to listen to" and Bonnie (42 years old) would "have [her friends] over or if they want to stay overnight" in an attempt to provide them with support.

Impact of Participants' Disabilities on Their Parents

During the discussions of the participants' relationships with their families, the parents reported on the impact of their children's disability on them personally. It is important to note that this category does not contain information from Bonnie (42 years old) and Lyle (63 years old). Bonnie's parents were not active participants in this project; therefore, I did not have their perspective. Lyle's parents had been deceased for many years prior to this project. Consequently, the impact of his disability on his parents was not relevant to his current story. For all other participants, Stephanie (6 years old), Kurtis (12 years old), Nicole (15 years old), and Erica (28 years old), the parents discussed the stress that they feel as parents of children with disabilities. They stated that raising a child with a disability can sometimes be overwhelming and that their children's inclusion could be very time consuming and cause increased responsibility. For instance, Erica's (28 years old) mom, Susan described several incidents that caused her to spend many hours working with Erica on her schoolwork and therapy.

> I worked part time, and so every night when we had speech stuff to do and there would be exercises—then, I think, through school, basically it became almost a role of us being tutors to [Erica] because she read so much more slowly than everyone else and she wrote—it took her a lot longer to do things. So I think it was just hard to juggle all that and fit it in and give her the time that she needed for the extra help.

Other researchers in the field of special education have acknowledged this increased stress that some parents of children with disabilities may cope with (Dyson, 1997; Glidden, Billings, & Jobe, 2006; Oelofsen & Richardson, 2006). Oelofsen and Richarson (2006) found that, compared to parents of children without disabilities, parents of children with developmental disabilities reported higher levels of stress, with 84% of mothers and 67% of fathers falling in the clinical range of stress. Similarly, Dyson (1997) found similar results in which parents of children contended with higher levels of stress than parents of children without disabilities.

Some parents also discussed the positive aspects of parenting a child with a disability. For example, the mothers of Stephanie (6 years old) and Erica (28 years old) reported that their daughters' disabilities increased their awareness of diversity and community inclusion, a unique learning experience that they might not otherwise have had. This is similar to Wolery and Wilbers (1994) acknowledgement that others can gain awareness about diversity and disability through their interactions with persons with developmental disabilities. This awareness is not only gained by peers but, as demonstrated through this project, parents can also be provided with a learning experience.

Impact of Participants' Disabilities on Their Siblings

In addition to the impact on the parents, the parents/guardians also acknowledged the impact of the participants' disabilities on their siblings. Stephanie (6 years old) must be excluded from this category because she is the only child in her family. In addition, because I did not interview Bonnie's (42 years old) siblings or parents for this study, I am also excluding her from this category. The parents/guardians of the other participants reported that having a sibling with a disability offered the nondisabled siblings a unique learning experience, thus, again, lending support to Wolery and Wilbers (1994) research. Meyer (1993) reported an unmet need for information regarding disability, which is contrary to the findings within this category. He reported some positive outcomes for the siblings but increased learning was not one of them

In a more negative light, for Kurtis (12 years old) and Nicole's (15 years old) parents, logistical challenges were the focus of the discussion. Kurtis' (12 years old) parents reported that his disability sometimes resulted in decreased opportunity to attend community social events for his sisters. For example, Kurtis has severe food allergies that prevent his family from attending community events in which a meal is served so often his siblings do not attend the community events either. For Erica (28 years old) and Lyle's (63 years old) siblings, the emotional challenges of having a sibling with a disability emerged. At times, having a sibling with a disability can cause feelings of increased responsibility and guilt. For example, Susan, Erica's (28 years old) mom, described how Erica's brother felt pressured to protect his sister in junior high. Meyer (1993) reported similar sibling impacts such as increased guilt and caregiving demands.

Support Received From Parents

Both the participants and the parents/guardians in this study acknowledged the support that the parents/guardians offered their children who have disabilities. The three youngest participants, Stephanie (6 years old), Kurtis (12 years old), and Nicole (15 years old), saw social/emotional support as the main source of parental assistance; it included assisting in the formation of friendships, scheduling and supervising social activities, and having high expectations that their children can strive to meet. Nancy, Stephanie's mom described how she attempts to set up structured social activities for Stephanie (6 years old) in order to assist her in meeting new people and forming meaningful relationships. This is similar to the parental social/emotional support reported in past research (Bhavnagri & Parke, 1991; Keachie, 1997; Ladd & Hart, 1992). These researchers discussed the important role parents played in helping their children initiate social interactions by organizing social events or gatherings for them.

Though previous research has focussed solely on the emotional/social support provided by parents, one additional form of support was discussed among the participants in this project. Among the adult participants, Erica (28 years old) and Lyle (63 years old) reported more logistical or material support. Some examples of this type of support were financial assistance and transportation. It would seem that, because the parents of the younger participants see their children every day, it is easier for them to provide direct social/emotional support; whereas the parents and siblings of the older participants may not spend as much time directly interacting with their family members, and logistical or material support is easier to give because this kind of assistance can be provided in a shorter time span.

Support Received From Siblings

Kurtis (12 years old) and Nicole (15 years old) reported having received physical support from their siblings, whereas Nicole (15 years old), Erica (28 years old), and Lyle (63 years old) reported sibling social/emotional support. Geisthardt et al.'s (2002) findings are comparable to those of Nicole (15 years old), Erica (28 year old), and Lyle (63 years old): The siblings of their participants acted as potential social partners for their siblings with disabilities and provided opportunities for them to meet potential friends. This support makes the environments in which the participants with disabilities interact more conducive to social interactions. Only Lyle (63 years old) reported that his sibling provided for him financially. Lyle's parents had been deceased for many years, and his sister felt that she should provide for Lyle (63 years old) in the way that her parents would have. This sibling concern is in line with Gorelick's (1996) findings; he found that a major concern for the siblings of persons with developmental disabilities was the aging or death of their parents thus leaving them as providers for their brother/sister with a disability.

Support Given to Siblings

Lyle (63 years old) and Nicole (15 years old) listed ways in which their siblings support them, but even when asked directly, "how do you help your brother/sister?" they could not identify any way in which they return this support. Similarly, at first, Kurtis (12 years old) reported that he does not help his sisters in any way, but with some parental prompting, he stated that he assists them physically in completing their chores. In comparison, Erica (28 years old) and Bonnie (42 years old) claimed that they return their siblings' emotional support by socializing with them. Erica (28 years old) reported that she supports her brother by "listen[ing] to him, and if he wants to do something, I might do it." This is another topic in the area of social inclusion that has been largely overlooked. Most research on siblings of persons with disabilities focuses on the role of the sibling as the supporter rather than the reverse scenario. Few researchers have directly asked about the support persons with developmental disabilities can provide their siblings, therefore leaving an important topic untouched.

Support Received from Extended Family Members

In addition to support from immediate family members, four of the participants, Stephanie (6 years old), Kurtis (12 years old), Nicole (15 years old), and Erica (28 years old), considered extended-family support an important component of their lives. In these cases, extended family was a broad term that included any relative outside of the immediate family (i.e., aunts, uncles, grandparents, and cousins). Bonnie (42 years old) and Lyle (63 years old) did not report any extended-family support because they have little contact with any relatives aside from their immediate family. However, all other participants identified emotional support as the primary assistance that they receive from their extended family. Extended family members have accepted the participants unconditionally and offer encouragement when they need it. For example, Stephanie's mom, Nancy, described how her extended family accepts Stephanie (6 years old) unconditionally: "she is just one of the family." Kurtis' (12 years old) mom reported similar support and stated that, even though she may not have continuous contact with her relatives, she knows that she can rely on them for anything. In Erica's (28 years old) case, she had close relationships with many of her family members and valued family activities such as water-skiing. Susan, Erica's mother, described these relationships further and stated that Erica (28 years old) received a great deal of support from her family:

> My mom was a big support, huge support for [Erica], and she passed away in 2002. She was probably one of [Erica's] best friends; they just had a wonderful relationship.

Furthermore, Susan reported that her extended family (i.e., aunts, uncles, grandparents) provides respite care when Erica (28 years old) requires it. This was not a theme that emerged from the youngest participants, Stephanie (6 years old), Kurtis (12 years old), and Nicole (15 years old). The parents of the younger participants were able to easily access babysitters for their children, but finding respite care for the adult participants proved to be more difficult, and they relied on family members to fill this need.

In the past, limited research has examined the role of extended family members in the lives of persons with disabilities. Only two studies (Day & Harry, 1999; Geisthardt et al., 2002), acknowledged extended family members, and those two studies include only a brief discussion of cousins as playmates and do not acknowledge the role that other relatives may play in the individuals' social inclusion. The results from my study, however, demonstrate the importance of support from all types of extended family members in the lives of some individuals with developmental disabilities.

Other Types of Relationships

The participants in this study described not only family and friend relationships, but also other types of relationships that they have in school, work, and other community settings. The types of relationships that the participants seemed to value differed across cases. In the cases of Stephanie (6 years old) and Kurtis (12 years old), the parents discussed their children's relationships with various community members, such as doctors, neighbours, and their parents' friends. Stephanie's (6 years old) mother, described the numerous types of relationships Stephanie had in the community including relationships with her parents' friend and grandparents' friends. According to Nancy, Stephanie (6 year old) was able to distinguish between these relationships and had been taught about the "safe" people she was allowed to talk to; her parents taught her "who makes a stranger, when it is okay and not okay to talk to someone." In discussing Kurtis' (12 years old) community relationships, his parents referred to a "rural advantage" similar to the one that Ralph and Usher (1995) discussed. According to Lena and Neil, Kurtis (12 years old) has benefited from living in a rural community because the community members have known him all of his life and accept him for who he is as an individual. The rural community has fully accepted and included Kurtis (12 years old) in all aspects of the community because that's "just the way he is" (Neil, Kurtis' father). Both Lena and Neil thought that Kurtis (12 years old) was receiving better treatment in his rural community than he would in an urban centre. According to Ralph and Usher (1995) rural communities are often better defined and have higher rates of interpersonal interaction because there is more opportunity to meet neighbors and other community members. It seems that Kurtis' increased opportunity to interact with his neighbors has resulted in full acceptance within his community. He is seen as an individual rather than a person with a disability.

In Stephanie's (6 years old) and Kurtis' (12 years old) parents' reports, most emphasis was placed on community relationships, with little conversation about school relationships unless the topic was deliberately broach by the interviewers. However, the teachers of both of these children described the relationships that they have developed in school (e.g., classmates, group members, acquaintances). The teachers discussed how Stephanie's (6 years old) and Kurtis' (12 years old) relationships with their school peers differed from the relationships the peers had with each other. At times Stephanie's and Kurtis' classmates viewed them as vulnerable and attempted to take on a caretaker role. The teachers stated that they often have to redirect the peers and stop these types of interactions to foster Stephanie's and Kurtis' independence. This finding is consistent with Hall's (1994) and Strain's (1984) discussions of the "baby brother/baby sister" relationship that some elementary school students have with their peers with disabilities. Sometimes, in an attempt to be inclusive, peers enter an "I'll help" relationship (Meyer, 2001) with the individual with a disability and become overprotective or "mothering" to the child (Hall, 1994; Strain, 1984). According to their teachers, Stephanie (6 years old) and Kurtis (12 years old) were, overall, accepted amongst their classmates. Kurtis (12 years old) however, was not always able to form intimate friendships with his classmates and had more acquaintance-type relationships with them. For example, Kurtis' teacher stated, "so he has found ways of playing outside around other students so it looks like he's playing, and he's having a wonderful time, but I don't see a friend." In addition, both Stephanie (6 years old) and Kurtis (12 years old) have experienced occasional incidences of bullying in school. These incidences were reported as being rare but did affect the participants and their families. For instance, Stephanie (6 years old) did not want to return to school after being bullied by a male classmate and Kurtis' sister became very emotional when she witnessed her brother being bullied.

Different from Stephanie's (6 year old) and Kurtis' (12 years old) parents' focus on community relationships, Nicole (15 years old) and her mom focussed on school relationships for most of the discussions on Nicole's social inclusion. According to Katherine, Nicole (15 years old) did not have many relationships outside of her schoolmates aside from her best friend and classmates from her former school. School seemed to be Nicole's main source of social opportunity.

Erica's (28 years old) and Bonnie's (42 years old) reports demonstrated yet another shift in perspective. Aside from family and friends, they focussed mostly on work relationships (e.g., co-workers, employer-employee). This seems intuitive because many adults are career oriented at this stage of their life and spend a great deal of time at their work. According to Henderson and Argyle (1985), several types of work relationships can be formed in various workplaces, including work acquaintances, work friends, and social friends. This, of course, depends on the "work culture" (Hatch, 1993) that sets the social atmosphere of the work setting. Bonnie and Erica described all three of these relationships in their discussions of their workplaces, which thus suggests that their work cultures fostered social inclusivity.

In addition to her work relationships and her relationship with her husband, Norm, Bonnie (42 years old) also discussed relationships that have formed as a result of her attendance at church. In fact, both Bonnie (42 years old) and Lyle (63 years old) discussed the important role of church in their lives. Lyle (63 years old) named only church interactions in addition to his family and friend interactions. Because he does not work, he relies on this network for social interactions. Similar to these results, past literature has identified church as a natural support network for persons with disabilities with its built-in structure that focuses on helping those who face challenges (McNair & Swartz, 1997; Sarason, 1977).

Benefits of Social Inclusion

Benefits to the participants. The parents/guardians of all of the participants agreed that social inclusion has presented their children with numerous learning opportunities. The participants have learned social and life skills from their nondisabled peers. Stephanie's mom stated that Stephanie (6 years old) "sees what [her peers] do and learns how to behave or misbehave—just how to react" because she is socially included. Kurtis' (12 years old) mom made a similar statement; "[social inclusion] forces him to make some decisions on his own" therefore teaching him how to cope with various situations. Bonnie (42 years old) also acknowledged the learning benefits of inclusion in her interviews: "It just gives me more skills and more learning." Much of the previous literature that focussed on the benefits of social inclusion has also acknowledged this learning opportunity (e.g., Cole & Meyer, 1991; Ensign, 1993; Schleien et al., 1990; Schleien et al., 1997). Individuals with developmental disabilities learn appropriate behaviour and self-help skills when socially included (Schleien et al., 1990; Schleien et al., 1997). This was a topic that was important to Lyle's sister. She thought that social inclusion motivated Lyle (63 years old) to "be a cleaner person." Furthermore, persons with disabilities can also learn social skills from their peers (Ensign, 1993), a point that Stephanie's mom stressed as important. In fact, Cole and Meyer (1991) found that children with disabilities who were socially included in regular classroom events scored higher on the Assessment of Social Competence Scale than did children who were placed in a segregated environment.

In addition to the learning benefits of social inclusion, Stephanie's (6 years old) and Kurtis' (12 years old) mothers saw social inclusion as an important opportunity to network with community members. Much like Turnbull and Turnbull's (1991) definition of friendship, both mothers thought that social inclusion provides opportunities to build a network in the community that can benefit their children later in their lives. Moreover, Nicole's (15 years old) mother considered social inclusion a means of increasing Nicole's self-confidence because she had opportunities to interact successfully with her peers. According to Reidy (1993), social inclusion can bring a sense of belonging and personal fulfillment to individuals with developmental disabilities, which, in turn, increases their self-confidence and self-concept. It is important to note, however, that, during the interviews, not all aspects of social inclusion were viewed ass beneficial. At times, challenges, such as bullying and isolation, were faced. These challenges will be discussed in more detail later in this chapter and will be included with the *social challenges* discussion.

Benefits to others. Similar to discussions in past research (Meyer, 1991; Labelestra, 1991; Wolery & Wilbers, 1994), the discussions in this study focussed on the benefits, not only to the participants, but, when asked, "what are the benefits of inclusion?" some of the participants, parents/guardians, and teachers/employers discussed also discussed the benefits to others. Bonnie (42 years old) and Lyle (63 years old) however, identified no additional benefits aside from the personal benefits stated above. For Stephanie (6 years old). Kurtis (12 years old), Nicole (15 years old), and Erica (28 years old), however, the parents/guardians and teachers/employers reported that social inclusion offers other individuals opportunities to learn about diversity and differences. In fact, according to her employers, Erica (28 years old) is a role model for other families and children who face challenges. Wolery and Wilbers (1994) and Myers (1991) also discussed this benefit to those who interact with persons with disabilities: The nondisabled peers often have unique opportunities to learn about diversity, challenges, and strategies to overcome these challenges. In Meyers (1991) research, he even describes one case in which a parent describes how her son's classmate with a disability taught him to face challenges in an appropriate manner.

A unique benefit that Kurtis' teacher and Stephanie's mother discussed is that the children's personalities often add to the social environment in their school. Kurtis (12 years old) often does special things for his friends, such as making birthday cards, while Stephanie (6 years old) displays a good sense of humour that her peers enjoy very much. This is not to say that their personalities always add to the social environment. At times, according to his teachers, Kurtis will display immature behaviour that discourages social interactions and he does not always have the same interests as his peers. According to his mother, Kurtis (12 years old) "wouldn't carry on the same sort of conversation that other boys his age would with people." It seems that, though Kurtis does contribute to his school in a personal way, there are also challenges that he faces in this arena.

Social Challenges

During the interviews, the participants, parents/guardians, and teachers/employers identified several social challenges that the key participants faced. Despite the fact that many of the participants have had positive social experiences, they have all experienced some type of challenge in their social inclusion. Stephanie's (6 years old), Kurtis' (12 years old), Nicole's (28 years old), and Lyle's (63 years old) parents/guardians and teachers/employers all reported that the participants have, at times, socially isolated themselves and reduced their own opportunities for social interaction. These participants have shown a desire to spend time alone or interact with adults rather than take part in activities with their peers. The parents/guardians of Nicole (15 years old), Bonnie (42 years old), and Lyle (63 years old) referred to self-consciousness that led to lowered self-confidence and, at times, a reluctance to take part in some social activities. For example, Norm, Bonnie's (42 years old) husband, discussed how Bonnie's lack of confidence in her abilities resulted in lost opportunities at work. Bonnie (42 years old) had a desire to try working with older groups of children in her day care, but because "the disciplining is different [and difficult] for her" (Bonnie's husband, Norm), she was not able to make this transition. In Nicole's case, her teaching assistant reported a similar lack of self-confidence that prevented Nicole (15 years old) from taking part in social activities.

> But I think she sees herself as not being the same as them, and so I think she honestly feels that she doesn't fit with them, because a lot of times the other girls will run off and they'll go down to the corner store or something like this, but [Nicole] will never go—ever, ever, ever. No. She'd say, "No, I'm going to stay in" or "No, I have to heat up my lunch," or "No, I'd rather not."

Rosenberg (1965) reported that low self-confidence and self-concept can result in self-rejection and self-contempt and damage an individual's social life. In this study, Nicole (15 years old), Bonnie (42 years old), and Lyle (63 years old) were aware of their disabilities and differences and this caused them to lack confidence in their abilities in school, work, and leisure activities, thus, resulting in a reluctance to move beyond their "comfort zone" and try new things.

It is important to note, however, that, though the parents and teachers viewed this self-isolation as a challenge, Nicole (15 years old), Bonnie (42 years old), and Lyle (63 years old) reported that they, at times, preferred to be spend time alone. Nicole (15 year old) reported that spending time alone "gives me time to think" while Lyle (63 years old) said, “sometimes I like to be alone.” In Bonnie’s (42 years old) case, she reported that she did not mind spending time by herself because she kept busy with hobbies such as cooking. It seems that, though self-isolation is sometimes a concern for the parents and teachers of these three individuals, their self-isolation may simply be a choice and a need for “alone time.” It seemed that if they were surrounded by other people all the time, they became overwhelmed and did not have the time they needed to do the things they liked to do on their own.

An additional challenge that the adult participants, Erica (28 years old), Bonnie (42 years old), and Lyle (63 years old), and their parents/guardians identified is a lack of essential resources. The parents/guardians discussed a lack of adequate support in the form of special programs or financial aid that has interfered with the participants’ social inclusion. In particular, Erica’s (28 years old) and Lyle’s (63 years old) guardians were frustrated with the constraints that AISH funding has put on their family members. For example, AISH limits the amount of income that a person with a disability can earn before his/her benefits are reduced, which thus discourages the participants from working more hours. According to Virginia Commonwealth University Department of Rehabilitation Counselling (1989), financial support is a concern for many individuals with developmental disabilities. In their report, issues of financial welfare dominated perceptions of well-being and though many individuals with disabilities were generally satisfied with the direct services they were receiving, satisfaction with supports was low. Given the reports of lack of resources from some of the participants in this study, it seems that lack of financial supports still exists for some individuals with developmental disabilities.

Furthermore, as a third emerging theme for social challenges, all of the participants except for Lyle (63 years old) had experienced bullying in their social inclusion. This bullying was most often verbal. For example, Bonnie (42 years old) and Kurtis (12 years old) were both victimized by their peers because of their differences. Kurtis (12 years old), his parents, and his teachers all discussed incidents of bullying that Kurtis (12 years old) had been faced with during his schooling. Kurtis discuss his frustration with one bully by stating "That boy! He is such a bully!" His teachers stated that, on occasion, Kurtis' peers would make negative comments about Kurtis to his sister thus making her a target of the bullying as well. According to Bonnie's husband, Bonnie (42 years old) had endured criticism in the past " 'because you're at a different level' or 'the way you look', or 'you're three hundred pounds' or whatever [illegible]ase may be." Furthermore, Bonnie (42 years old) was recently bullied by persons in her neighbourhood when her bicycle was stolen and vandalised. Piek, Barrett, Allen, Jones, & Louise (2005) found that, even though bullying is not uncommon among all people, both those with disabilities and those without, it can, sometimes, affect persons with disabilities at a greater level. In particular, they found that girls with a developmental coordination disorder had their self-worth more negatively impacted by peer aggression than the comparison group of children without disabilities.

Other challenges that the parents/guardians reported were unique to individual participants but seemed to be a factor of age. Stephanie's (6 years old) mother discussed the struggle that she and her husband faced in deciding when to tell Stephanie and her peers about her disability. She does not want Stephanie (6 years old) to be "blindsided" by the fact that she has a disability but, at the same time, she is reluctant to place a label on Stephanie (6 years old) at such an early age. This is a struggle that seemed appropriate at this age because it is often a time face when children begin to notice differences between themselves and their peers (Cole, Cole, & Lightfoot, 2005). In addition, according to previous literature, it seems that this concern is one that holds some merit because some labels are too generic and do not adequately address the needs of individuals, and others are too narrow and pigeon-hole individuals into constraining categories (Gooloo, Wunderlich, Rie, & Amado, 2002). Therefore, parents must be careful when placing these labels on their children.

Kurtis' (12 years old) parents and teachers described the developmental gap that was forming between Kurtis (12 years old) and his peers. Kurtis has different interests from those of his peers and, in some activities (e.g., sports) Kurtis' skills were not advancing at the same rate. This challenge seemed fitting at this age because, as children grow older, their skills begin to advance (Cole, Cole, & Lightfoot, 2005), but if a disability interferes, this skill advancement may be delayed.

For Erica (28 years old), social challenges involving intimate relationships were a concern. At the time of her interviews, Erica (28 years old) had no interest in romantic relationships, which, at times, caused tension between her and her friends. According to both Erica (28 years old) and her mother, some of Erica's friends would pressure her to become romantically involved, whereas others became jealous of her when she interacted with their boyfriends. According to Susan (i.e., Erica's mother), this has caused Erica (28 years old) a great deal of distress because she is unsure of how to deal with these situations and lacks social maturity. The young-adult years are often focussed on building romantic relationships or searching for a partner, but Erica (28 years old) had not yet reached this stage. Individuals with developmental disabilities have varying degrees of sexual interest just like the rest of the population but this population needs the same love, affection, and interpersonal relationships as most people (Di Giulio, 2003) regardless of whether they want to pursue romantic relations or not.

Finally, Lyle (63 years old) and his sister discussed physical challenges that sometimes interfere with his social interactions. Lyle (63 years old) is not able to walk for long periods of time, and this challenge limits his social activities on vacation with his family or on outings with his peers. For many people in the senior-citizen years, age-related physical challenges often become a reality that they face. In addition, some persons with disabilities have conditions that can exacerbate such challenges and cause further difficulties. Schleien et al. (1997) identified physical limitations as an internal barrier to social inclusion for many individuals with developmental disabilities and, according to self-reports and family reports, this is something that Lyle (63 years old) struggles with regularly.

Revisiting the Socio-Ecological Model (1967) and Social Comparison Theory (1954)

In an attempt to summarize the cross case comparisons, it is useful to look at the findings in light of Bronfenbrenner's Socio-Ecological Model (1967). Bronfenbrenner (1967) identified four complex layers of an environment that have an effect on an individual's social development: the microsystem, the mesosystem, the exosystem, and the macrosystem. The microsystem is the immediate face-to-face setting in which an individual is a direct participant while the mesosystem includes the interactions between microsystems. "Safe" microsystems need to be set up to encourage rather than discourage social interactions. For example, the structured settings that, according to their parents, Stephanie (6 years old), Kurtis (12 years old), and Nicole (15 years old) need to successfully interact with their peers act as microsystems that are conducive to social interactions. These structured activities allowed for the parents or teachers/employers to monitor the social interactions and intervene when challenges such as isolation or bullying occurred. Furthermore, all participants discussed how structured settings such as birthday parties or Special Olympics assisted them in meeting potential friends and forming new friendships. Erica (28 years old), Bonnie (42 years old), and Lyle (63 years old) were able to carry these relationships beyond the structured setting once the initial friendship formation had begun. This suggests what Bronfenbrenner (1967) would describe as a mesosystem: social interactions in the structured settings (i.e., microsystems) increase the participants' chances for success in less structured settings (i.e., future microsystems).

In addition to the parental support and structured settings, reports of friend and sibling support also seemed to be components to building microsystems conducive to friendship development. For example, three of the participants, Stephanie (6 years old), Kurtis (12 years old), and Bonnie (42 years old) described how their friends provide them with physical assistance when they need it. This physical assistance helps in ensuring that natural interactions occur in the various microsystems without unnecessary interference from support personnel or parents. In fact, Bonnie (42 years old) received support from her friends throughout her college program rather than receiving support from the disability assistance program at her college.

Siblings also provide support that affected the interactions within the microsystems. Erica (28 years old) and Bonnie (42 years old) discussed how their siblings take an active role in their social lives and assist them in meeting potential friends. Moreover, their siblings provide emotional support that encouraged them in other social settings, thus acting as a mesosystem.

Within these findings, there was also reference made to two important exosystems. An exosystem is a context in which an individual is not actively involved but is influenced by (Bronfenbrenner, 1967). The activities that occur in the exosystem can alter the characteristics of the individuals' microsystems. In the cases of Erica (28 years old), Bonnie (42 years old), and Lyle (63 years old), their parents/guardians discussed how a lack of essential supports acted as a barrier to their social inclusion. Erica (28 years old) and Bonnie (42 years old) did not always have their needs met during their schooling because there was an administrative resistance to modifications such as extra time to write exams or opportunity to work in smaller groups. In addition, Lyle's (63 years old) and Erica's (28 years old) parent/guardians discussed the importance of recreational programs for persons with disabilities and how there is a need for more such programs. Thirdly, lack of financial support for persons with disabilities was a source of frustration for Erica's (28 years old) mother. These reports of lack of essential supports indicate a need for policy makers (i.e., the exosystem) to review their agendas and policies and make changes to better meet the needs of the individuals with disabilities and support microsystems conducive to social inclusion.

As the fourth layer in Bronfenbrenner's Socio-Ecological Model (1967), the macrosystem also seemed to play an essential role in the social experiences of the participants with developmental disabilities. The macrosystem includes the overarching culture that encompasses the microsystems, mesosystems, and exosytems

(Bronfenbrenner, 1967). Within each macrosystem, there can also be subcultures that have their own norms and values. Three such subcultures were described within this research: the community culture, the work culture, and the church culture. Kurtis' parents described the "rural benefits" that Kurtis (12 years old) had received from growing up in a small community. Within the community, Kurtis is viewed as an individual rather than as a person with a disability. This suggests that his rural community has built a subculture (i.e., a macrosystem) of acceptance where "that's just him" (Kurtis' mother, Lena). For Erica (28 years old) and Bonnie (42 years old), they have experienced co-worker relationships that have moved beyond the workplace and resulted in friendships. According to Hatch (1993), building these types of relationships is dependent on the "work culture" of the employment setting. It seemed that the "work culture" for these two participants was one of acceptance, support, and social inclusion. Bonnie (43 years old) also described the social relationships she has been able to form in her church. Past literature has identified church as a natural support network for persons with disabilities, with its built-in subculture that focuses on helping those who face challenges (McNair & Swartz, 1997; Sarason, 1977). With this support, Bonnie (42 years old) has been able to meet potential friends and form meaningful relationships.

While much of the data in this research was focused on the contexts in which the social interactions took place, it is important to note the role of Festinger's Social Comparison Theory (1954). Not all social experiences identified in this research were positive in nature and, in some cases, it appeared as though social comparisons may have played a role. Social comparisons are those that individuals make between themselves and others in their immediate comparison group in an attempt to generate self-evaluative information (Coleman, 1983; Morvitz & Motta, 1992; Schurr, Towne, & Joiner, 1972; Schwalbe, Gecas, & Baxter, 1986). These comparisons can help to maintain self-concept but can often lower self-concept. Nicole's (15 years old) teaching assistant, Bonnie's (42 years old) husband, and Lyle's (63 years old) sister all reported on the awareness these participants had about their disabilities and differences. According to these significant others, the participants lacked self-confidence because of this awareness and were reluctant to take part in certain activities. These reports suggest that, perhaps, the participants are comparing themselves to their nondisabled peers and becoming self-conscious because of their perceived differences, thus suggesting that, though there were many positive experiences reported by the participants and their families, social comparisons can still be damaging and care needs to be taken to counteract these comparisons. One such solution may be that described by Erica's mom. Erica's (28 years old) participation in an outing group for persons with disabilities allowed Erica to gain confidence by acting as a "helper" to her peers rather than being the receiver of help all of the time.

Future Directions

Practical Implications

The findings from this research suggest several considerations for the social inclusion of persons with developmental disabilities. Underlying many of the themes is the need for social-skills training. The mothers of Stephanie (6 years old), Kurtis (12 years old), and Erica (28 years old) discussed the importance of training in areas such as the meaning of friendship, friendship skills, and romantic relationships and suggested that, though their children were socially included, their lack of understanding in some social situations (e.g., romantic interactions) has caused frustration and anxiety. In addition, bullying incidents were reported across all cases except for Lyle (63 years old), which indicates a need for individuals with developmental disabilities to learn strategies to manage peer aggression. Each participant had general strategies to form friendships (i.e., introducing oneself and getting to know the other person) but would most likely benefit from training in further strategies in maintaining friendships and resolving conflict. In addition, self-isolation was often a challenge for Stephanie (6 years old), Kurtis (12 years old), Nicole (15 years old), Bonnie (42 years old), and Lyle (63 years old). Parents, teachers, and peers have attempted to assist in the participants' social inclusion, but these participants have chosen to spend time alone and do not display interest in taking part in activities with their peers. This suggests that, perhaps, they do not know how to effectively interact in some contexts and choose to be by themselves rather than risk embarrassment. For example, Nicole's teaching assistant suggested that Nicole's awareness of her disability and differences prevented her from taking part in activities such as going to the local store with her friends. At other times, some of the participants (i.e., Nicole, 15 years old; Bonnie, 42 years old; and Lyle, 63 years old) reported that they liked to be alone. Nicole (15 years old) reported that being alone gave her time "to think" and Bonnie (42 years old) stated that she sometimes enjoyed hobbies such as cooking or bike riding on her own. This suggests that, while social relationships seem to be important to these individuals, they are sometimes more important than other times. Persons with disabilities should not be forced to spend time with their peers if they do not show a desire to do so; some time alone seems to be important in many of the cases presented above.

To further assist individuals with developmental disabilities in their social inclusion, it seems that structured activities and special events might be needed. The younger participants in this project have relied on structured activities as a context that encourages successful social interactions, whereas the older participants meet potential friends and form relationships through structured environments. In addition, most of the participants reported the personal importance of special events such as birthday parties or conferences. It seems that it is not enough to equip persons with disabilities with effective skills and strategies, but that parents, support staff, and other community members may also need to provide "safe" settings that encourage and provide opportunities for social interactions.

Implications for Future Research

In addition to the practical implications of this research project, there are also several implications for future research that are illuminated in the findings. The findings of this research clearly identified social supports as a critical factor in the lives of individuals with developmental disabilities and, therefore, it is important that the research community continue to research strategies to promote friendships and other social relationships in all contexts. More specifically, the supports and benefits discussed in this dissertation (i.e., parents, siblings, friends, extended family, etc.), most prominently include informal social supports for persons with disabilities. Further research needs to be conducted on how to better build informal social supports into the lives of persons with disabilities and how to avoid or prevent "caretaking" or "babying" interactions. For example, a study into the informal supports that rural communities may offer persons with developmental disabilities may be warranted. As reported by Kurtis' (12 years old) parents, living in a rural setting allows community members to know the child as an individual and provide him/her with individualized support. Also, according to Turnbull et al. (1999), with increased visibility comes increased acceptance, which can add to the socially inclusive nature of the community culture. Formal supports are at times essential but, as this research shows, they are not always sufficient and, according to the parents/guardians, often not available.

Additionally, future research needs to investigate the current definitions of inclusion. In the past, many educators and family members have perceived inclusion as involving persons with disabilities in interactions with nondisabled peers in "regular" environments. However, my research has identified the important role that peers with disabilities can play in the social inclusion of persons with developmental disabilities. Moreover, according to both the participants and the parents in this project, not only is inclusion about setting; but social relationships must also be present for true inclusion to occur. A broader definition of inclusion, like the definition of social inclusion presented at the beginning of this dissertation, is needed to include such characteristics. Also, it is important that we further investigate the role that peers with disabilities can play in the social inclusion of persons with developmental disabilities.

Furthermore, I suggest that the definition of friendship be revisited to include the concepts that the individuals with disabilities identified in this research. Many of the participants' definitions of friendship were different from those reported by their parents. This does not, however, make the friendships of these individuals any less meaningful. To many of these participants, their friends are an essential part of their lives and play important roles in supporting their social inclusion. Without these friends, many of the participants would be at risk for social isolation and lowered self-confidence. I suggest that the definition of friendship be broadened to include the relationships that the individuals with disabilities described (e.g., someone with whom they spend time or former support staff). To these individuals, these relationships hold value and constitute friendship. It is also important to further explore the perspectives of individuals with developmental disabilities to better understand such concepts. This perspective is often ignored but, as shown in these case studies, it is a viewpoint that can provide insight into many disability issues.

Research projects that include the perspectives of individuals with disabilities are an important contribution to the research community. Individuals with disabilities can help us to gain insight into their experiences, wants, and needs by participating in qualitative research. However, there are ethical and methodological considerations that need to be reviewed throughout the research process to ensure the safety of the research participants and the trustworthiness of the data and interpretation. To overcome these issues, it is important that any researcher planning to undertake a project with individuals with developmental disabilities keep four guiding questions in mind (Barton, 2005, p. 325):

1. For whom is my research?
2. What right have I to undertake this research?
3. What responsibilities arise from privileges that I have as a result of my social position?
4. Do my writing and speaking reproduce a system of domination and oppression or challenge it?

With these questions as guides, researchers will be able to maintain their awareness of the issues surrounding research with this special population. As a result, they will be able to approach the research in a moral and ethical manner while still upholding the trustworthiness of the data.

In addition, an inclusive research approach like that recommended by Kitchin (2000) could also be used to overcome any obstacles encountered during the research process. An inclusive research project is research conducted by a team of people both with and without disabilities. The presence of people with disabilities on the research team can help to better identify the needs of the participants with disabilities and can bring insight into the interpretation of the data. For this to happen, however, the people with disabilities have to become involved beyond being the subject source and be able to enter a true partnership with the researchers (Kitchin, 2000). To conduct qualitative research among individuals with disabilities in an ethical manner, researchers should first recognise the "expertise" of individuals with disabilities (Kitchin, 2000) and the vast knowledge that they are able to bring to the research setting.

Considerations

Within this research project are a few limitations that need to be acknowledged. First, the design of the study itself limits the extent to which the results are generalizable across all persons with disabilities. Conducting an inquiry across a larger number of participants would assist in distinguishing which findings are due to age and which are due to type of disability, gender, or individual experience.

Second, in some instances in the case studies, particularly in the cases of the youngest participants, Stephanie (6 years old) and Kurtis (12 years old), the parents' perspectives tended to dominate the data. They discussed several ideas and opinions at length, whereas the key participants answered with shorter, “surface” answers. Although the parents’ viewpoints were important in each case, one purpose of this study was to shed light on an underrepresented standpoint; that is, the perspective of persons with disabilities. Strategies to effectively draw out personal information from young participants with developmental disabilities would be an asset to this type of research, and, although I believe that I made some progress, further effort needs to focus on this dilemma.

Third, some challenges during the interview processes arose during the data collection for this study. At times the key participants needed to have questions worded in a more concrete or closed-ended manner. Furthermore, many topics discussed in the interviews evoked emotional responses from both the participants and myself. These two challenges made it difficult not to lead the participants to specific topics or answers. Most of the participants searched for answers that were “right,” and this may have limited their willingness to report on certain topics. To combat this difficulty I used two strategies. First, in the cases in which closed-ended questions were required, I used extensive probes to encourage the participants to clarify or expand on their answers. Second, bracketing was of utmost importance within this study. I journalled any responses that I had to individual interviews and any personal biases regarding the topic of inclusion. This approach assisted me in maintaining my awareness of my own subjectivities. Presenting these pre-understandings in the methods chapter of my research allows readers to better understand the “lens” through which I interpreted the results.

Finally, a fourth possible limitation is the bias that may have been present within this particular group of participants. I chose all participants from the larger Inclusion Across the Lifespan project, a study on "inclusive experiences" that, therefore, drew the attention of participants and parents who were biased in favour of inclusive ideology and practices. It is unlikely that families opposed to inclusion would volunteer for such a study. This consideration suggests that the sample in this project may be positively biased toward inclusion, which might have omitted some of the issues that would arise in the lives of individuals who have had negative experiences with inclusion.

Summary and Concluding Remarks

The study of social inclusion has only recently been at the forefront of special education research. In previous years researchers were most concerned with physically and academically supporting children with disabilities in "regular" classrooms, with little emphasis on the adult populations or contexts external to the school environments. Eventually, some studies began to demonstrate the benefits of social inclusion as well as the damaging effects of social isolation. In addition, Bronfenbrenner (1967) shed light on the important role of context in the social lives of persons with disabilities and reported on the factors that need to be present to encourage rather than inhibit social development at all levels of contexts (i.e., microsystem, mesosystem, exosystem, and macrosystem). Still, little emphasis was being placed on social inclusion in adulthood, and many studies focussed only on the perspectives of parents/guardians or educators, thus ignoring an important viewpoint, that of individuals with disabilities. Through the case studies highlighted in this dissertation, I have presented the unique perspective of 6 participants who differ in age. Comparing results across cases illuminated many similarities and differences. It was during this exploration that I recognized the implications for future practice and research. These case studies revealed many social relationships and both positive and negative social experiences. Not only have the individuals with disabilities often benefited from their social inclusion, but so have their parents, siblings, and communities as a whole. However, despite the numerous positive social relationships and experiences that the key participants, their parents/guardians, and their teachers/employers reported, they also discussed social challenges. In addition to existing social supports, persons with developmental disabilities need to be further supported to overcome these challenges and reach their social goals. With essential social supports in place, the extent to which individuals with disabilities can lead rich and productive lives is immeasurable.

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APPENDIX A:

INCLUSION ACROSS THE LIFESPAN PROJECT SUMMARY

(IRVINE & LUPART, 2003-2006)

Purpose

The purpose of this project was to examine the inclusive experiences that children and adults with developmental disabilities encountered in school, work, and leisure settings. Six different age groups (i.e., 3-6, 7-12, 13-17, 18-30, 31-50, and 51+ years) were studied to explore inclusion over the lifespan. In addition, an investigation of three different perspectives (i.e., individuals with a disability, their parents/guardians, and their teachers/employers) was undertaken in the hope of gaining a more complete understanding of the experiences.

Methods

Participant recruitment was completed by contacting school boards and advocacy groups via telephone. With the assistance of the cooperating agencies and schools, interested families were then contacted through a mail-out. In the case of underage or "captive" participants, a consent form was sent to their parents/guardians prior to their participation in this study. Thirty-six individuals described by parents and teachers as having a mild-moderate developmental disability were selected for participation in this research and organized into the six respective age groups. Each group was comprised of five to seven participants. Following the initial sample selection, teachers/employers were also sent a consent form to participate in a supplementary interview.

Researchers gathered information from semi-structured interviews. Each key participant was interviewed two times over a three-year period. All interviews were approximately 15-30 minutes in length and focussed on the participants' perceived involvement in, feelings about, and reflections on everyday activities, such as recreation, education, and/or employment. In addition, where applicable, the parents/guardians and teachers/employers of each key participant were interviewed to gain supplementary information and compare perspectives. All interviews were audiotaped and transcribed verbatim.

Data Analysis and Interpretation

Given the qualitative nature of this study, the analysis and interpretation of the data were descriptive of the information obtained. A thematic analysis helped to identify trends across the six age groups as well as any potential differences between the perspectives of the participants, parents/guardians, and teachers/employers. To assist this process, NUDiST software was used to organize the data and identify trends and patterns in the interview transcripts.

Dissemination of the Inclusion Across the Lifespan Findings

At the closure of this project, all individuals involved were invited to take part in a wrap-up symposium offered by the investigators and their research teams. During this symposium, selected results were presented and information packages summarizing the remaining results were distributed. In addition to the wrap-up symposium, researchers have published and will continue to publish the results of this study in academic journals such as *Exceptionality Education Canada*, *Developmental Disabilities Bulletin*, *Exceptional Children*, *Education and Training in Mental Retardation and Developmental Disabilities*, and the *International Journal of Inclusive Education*. In addition to publications, results have been used to present the current state of inclusive practice and its influence on individuals with developmental disabilities to classes in courses on inclusive education.

APPENDIX B:

SAMPLE CONSENT FORMS

[redacted]

I, ______________________________, agree to participate in *The Importance of Social Relationships for Persons with Developmental Disabilities* project. This project has been explained to me. I understand that I will be asked some questions about my school/work and leisure activities and the relationships I have with people in these activities. This interview will be tape recorded and take about 1-1 ½ hours. During the interview, the researcher will ask me to draw some pictures to help me talk about the importance of these social relationships. I do not have to draw any pictures if I don't want. I give permission for the researcher to display my drawings in her thesis. My name and interview will be kept confidential. No one but the researcher and her team will know what I say. I understand that I do not have to answer any questions I don't want to. I can stop the interview at any time. I will keep a copy of the consent form. If I have any questions I can call (780) 492-0800 for Angie. I understand that I can contact the U of A Research Ethics Board at (780) 492-3751 if I have any concerns about the ethical conduct of this study.

Name: ______________________________ Date: ____________________

Phone: ____________________ Signature: ______________________________

[redacted]

I, ______________________________________ agree to participate and let my child participate in *The Importance of Social Relationships for Persons with Developmental Disabilities* project. This project has been explained to me. I understand that myself and/or my son/daughter will be asked some questions regarding my son/daughter's inclusion in school/work and leisure settings and the social relationships (i.e., friends, acquaintances, etc.) he/she has in these settings. These interviews will be recorded and take about 1-1 ½ hours. During the interview with my son/daughter, the researcher will ask my son/daughter to draw some pictures to help him/her better communicate the importance of their social relationships. My son/daughter does not have to draw any pictures if he/she does not wish to. I give permission for the researcher to display in her thesis any drawings my son/daughter produces during the interview process. My son/daughter's name and interview will be kept confidential. No one but the researcher and her team will know what my son/daughter or I say. I understand that my son/daughter and I do not have to answer any questions we don't want to. My son/daughter and I can stop the interviews any time we want. I also give permission for the researcher to contact my son/daughter's teacher/employer to interview him/her for this project. I will keep a copy of the consent form. If I have any questions I can call (780) 492-0800 for Angie. I understand that I can contact the U of A Research Ethics Board at (780) 492-3751 if I have any concerns about the ethical conduct of this study.

Child's Name: ______________________________ Date: ______________________

Phone: ________________________ Signature: ______________________________

APPENDIX C:

SAMPLE INTERVIEW QUESTIONS

Participant Interview

ACTIVITY 1: Draw me a picture of the people in your class/workplace. (I also asked for a separate picture of a leisure activity.)

1. Tell me about your picture.
2. Who is in this picture?
3. How do you know these people?
4. Are any of the people in this picture your friends?

ACTIVITY 2: Draw me a picture of one of your friends.

1. Tell me about the person in this picture.
2. Where did you meet him/her?
3. Why do you call him/her a friend?
4. What things do you like to do with this person

(Referred to pictures as I asked the following questions)

1. How many friends do you have?
2. How do your friends help/support you?
3. Where did you meet your friends?
4. How did you become friends with your friends?
5. Do your friends ever come to your house to visit you? How often?
6. Do you ever go to your friends house? How often?
7. Do you talk on the phone with your friends? If so, how long do you talk? How often?
8. Do you share secrets with your friends? Why or why not?

9. Do you and your friends like to do the same things? Can you give me an example?

10. Do your friends have disabilities? Do you have some friends without disabilities?

11. Does anyone help you to make friends? Who? How do they help?

12. Tell me about the other people in your class/workplace.

13. Do you spend time with your relatives? What do you do with them? Are they your friends, why or why not?

14. Do you have a best friend? If so, who?

    a. What makes you think of __________________ as your best friend?

    b. How did you become best friends?

    c. What does it mean when you say someone is your best friend?

15. What does it mean to be a good friend?

16. Where do you go to spend time with your friends?

17. How do you feel when you are by yourself?

18. Do you ever feel lonely? If so, why and how often? Are you by yourself or with other people when you feel this way?

19. How do you make friends?

Parent Interview

1. Does ________________ know a lot of people?
2. Where did ________________meet the people he/she knows?
3. Would you say these people are his/her friends or are they acquaintances?
4. How many friends does ________________have?
5. How did ________________________ come to be friends with these individuals?
6. Do___________________________’s friends have disabilities? Does he/she have friends without disabilities?
    a. What is the difference between his/her friends with disabilities and his/her friends without disabilities, if any?
7. What do you think is means to be a friend?
8. Why are friendships important?
9. What do you think are the factors that allow for friendship formation?
10. Do you help ____________________ make friends? If so, how?
11. Does anyone else help ________________________ make friends?
12. How do you think ___________________ benefits from his/her friendships?
13. How do you think ________________’s friends benefit from his/her friendship?
14. How do _________________ friends support him/her?
15. How does __________________ support his/her friends?
16. Does ___________________have a best friend? If so, what makes him/her ___________’s best friend?
17. Does ______________________have any difficulties with bullies? If so, how often? Where does this bullying occur? How does it affect ________________?
18. Are there any other types of relationships that ______________ has with people? Can you describe them to me?